AIDS FUNDING ISSUES—IMPACT AID, EARLY INTERVENTION, RESEARCH, AND PREVENTION

HEARING

BEFORE THE

TASK FORCE ON HUMAN RESOURCES

OF THE

COMMITTEE ON THE BUDGET
HOUSE OF REPRESENTATIVES

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SECOND SESSION

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AIDS FUNDING ISSUES—IMPACT AID, EARLY INTERVENTION, RESEARCH, AND PREVENTION

TUESDAY, MARCH 6, 1990

U.S. House of Representatives,
Task Force on Human Resources,
Committee on the Budget,
Washington, DC.

The Task Force met, pursuant to notice, at 1:10 p.m in room 210, Cannon House Office Building, Hon. Barbara Boxer, Chair, presiding.

Mrs. Boxer. The Task Force on Human Resources is very pleased to have this very important panel today on the AIDS issue. We will hear today from an extraordinary array of witnesses for this particular hearing, and that is appropriate because we are dealing with a problem of extraordinary dimensions.

I am going to ask the photographers if they could do their last shot for the moment because I need to relate to these witnesses. I can't see them. Thank you very much.

Since AIDS was first identified in the United States in 1981, it has claimed 73,000 lives. Over the next 2 years it is expected to take another 190,000 lives. As many as 1.4 million Americans are infected. Nonetheless, the President's proposed budget, which this Committee is looking over, does not even reach the $2.2 billion requested by President Bush's own Secretary of Health and Human Services.

The witnesses who will speak today will provide the facts to bolster our arguments for increased funding to fight this disease. Today's testimony will serve as a series of reports from the front, whose purpose is to ensure that we understand the nature of this enemy. However, among today's stories there will also be some successes. We will learn about the strategies that have met with success and the magnitude of resources needed to continue and build upon these successes.

Our first witnesses will give us an overview of AIDS funding issues. This overview will come from Elizabeth Taylor and my colleagues, our colleagues, Henry Waxman, Ted Weiss, who is caught in a little bit of a snowstorm, but he is on his way, and Nancy Pelosi, all of whom represent areas hit hard by the AIDS virus and all of whom are leaders in this very difficult fight.

After that, we will hear from panels on impact aid, early intervention, and research and prevention. The remarks that you make will help us to shape the battle over AIDS funding in the coming years, and will influence the larger debate over Federal priorities.

Finally, as we begin this hearing, I want to not only welcome our distinguished witnesses, but thank you for your services to the American people. To Elizabeth Taylor, I want to say that your involvement in this AIDS issue has been extraordinarily helpful in bringing attention, focus, and compassion to the fight against this epidemic. We know that your privacy is something that you value, and we know that you are giving it up to be here with us today. We thank you from the bottom of our hearts.

At this time I would ask the Chairman of the Budget Committee, Leon Panetta, who has been such a strong supporter of the fight against AIDS, to make a few comments if he wishes.

The CHAIRMAN. Thank you, Mrs. Boxer. I just want to thank you for the help that you are providing us in trying to confront this issue and extend a welcome to all the witnesses. I think all of us recognize that we live at a time of very dramatic changes going on across the world, and those changes are happening in large measure because the United States has really served as an example to other countries of what democracy is all about.

I think one of the keys to the success of our democracy has been our willingness to confront issues and concerns within our own society, that we are willing to not only deal with national security issues in terms of defense needs, but more importantly, we have dealt with national security concerns in terms of meeting human needs within our own society.

Surely, if those countries have the courage to be able to make the kind of tremendous sacrifices that they have made over the last few months, there is no reason why the United States can't make the same kind of sacrifice in confronting this kind of issue within our society, so we thank you for providing us, hopefully, the inspiration to doing the right kind of thing in trying to deal with this terrible disease within our own society.

Mrs. BOXER. Thank you, very much, Mr. Chairman.

Mr. Rogers, do you have a statement? Mr. Guarini?

Mr. GUARINI. Madam Chairman, I appreciate your calling these hearings and want to commend you for your leadership, particularly in this very important national issue. Our crisis of AIDS is certainly serious throughout America and the world. It demands a national commitment and a national policy, a comprehensive one, and these hearings and witnesses are an important part of that step forward.

Ms. Taylor, we want to thank you. The world of entertainment is certainly leading the way in attracting attention to the problem, mobilizing the forces and trying to help find solutions. We applaud your commitment and all the good work that you have been doing.

I don't think that our chairlady knew this, but Jersey City is second—that is my principal city—only to San Francisco in numbers of AIDS cases per capita. So I have a strong concern because of how it affects my particular community.

Equally important are those people who are in the front lines who will be testifying today because they all are part of the solution. I also want to single out Dr. June Osborn, who came to Jersey City only a few days ago, and lifted the spirits of the community and her commitment is very helpful in our trying to form a national policy and her work is certainly a source of inspiration.

So I think we can all work together to support the AIDS Commission and come on with these hearings and hope that the light that you have put on the issue will certainly assure the victims of AIDS that we are compassionate. We do want their friendship and we do want to support them every step along the way. So I thank you very heartily for all the good work that you have been doing. Thank you.

Mrs. BOXER. Thank you, Mr. Guarini. If you look over there at that chart you can see the kind of impact that you are feeling in your district as these cases begin to rise.

Mr. Durbin, do you have any opening comments?

Mr. DURBIN. No.

Mrs. BOXER. Mr. Bryant?

Mr. BRYANT. I would just like to say thank you, Madam Chairwoman, for putting this together. I represent the seventh largest city in America. We have a very large problem in this area. I would like to thank Ms. Taylor for coming here and drawing public attention to it.

Mrs. BOXER. Now it is our pleasure to welcome you really officially and ask you, Elizabeth Taylor, to present your testimony for the record.

STATEMENT OF ELIZABETH TAYLOR, FOUNDING NATIONAL CHAIRMAN, AMERICAN FOUNDATION FOR AIDS RESEARCH (AmFAR)

Ms. TAYLOR. Thank you, Madam Chairwoman. It is an honor for me to appear before this distinguished Task Force of the House Budget Committee. Thank you.

I have been involved in the fight against AIDS for many years now. I am committed to this struggle because the tragedy of AIDS has affected me very deeply. So many of us have seen those we love, friends and family members, die of this devastating disease. So far, AIDS has killed over 70,000 Americans. That is more than died in the Vietnam war. Up to 1 million Americans are infected by HIV, the virus that causes AIDS. All of these people are in grave danger. Incredible as it may seem, the darkest period of the AIDS crisis still lies ahead of us.

Over the past few years we have started to see progress—sometimes major progress. But I am afraid that we are entering a new, very difficult period in our fight against AIDS. Just when it seemed that society's compassion and understanding of AIDS was growing, we are witnessing a very disturbing resurgence of ignorance and misinformation about this disease.

For example, we have all heard recent reports that the number of new AIDS cases is slightly lower than expected. As a result, some people are suggesting that the worst of the AIDS epidemic will soon be over. We are also hearing that AIDS only threatens people who are perceived to be on the margins of our society, such as people of color and gay men. The thinly veiled message is that the majority of Americans do not need to care about AIDS. Finally, we are hearing complaints that Federal AIDS spending is too high, especially when compared to what we spend on other illnesses.

I am deeply concerned about these disturbing misconceptions about AIDS. They are misleading, wrong-headed, and very dangerous. Any suggestion that the worst of the epidemic is over or that it will not in some way affect the majority of Americans simply is not true. The cold, hard facts tell us a very different story.

First, according to the latest statistics from the Centers for Disease Control, the number of people diagnosed with AIDS will more than double in the next year and a half.

Second, the virus that causes AIDS continues to spread at an alarming rate. Women and people of color now constitute the majority of new infections, and many of these people are being infected through heterosexual contact.

Third, AIDS is an infectious disease—a deadly infectious disease that threatens an ever-growing number of people in the prime of life. Given the perils of AIDS, the resources we have so far devoted to this epidemic, rather than being extravagant are minor compared to the resources we have long devoted to research on other diseases.

I have talked to many doctors and people with AIDS throughout the country. They all tell me one thing: health care facilities for people with AIDS are already overwhelmed. Some urban hospitals are literally overflowing. There are no available beds—patients must spend days waiting for a regular room. AIDS is pushing our health care system to its limits and beyond, endangering all Americans. And yet, incredibly the worst is yet to come. The demand placed on these facilities for AIDS related health care is expected to double in the next year and a half.

That is why I am here today. I have come to urge you to endorse the plan outlined in the Comprehensive AIDS Relief Act introduced in the Senate today by Senator Kennedy and Senator Hatch.

The first letters of this bill appropriately spell C-A-R-E. This bill will provide urgently needed health care for people with AIDS and HIV infection, and it can help save our health care system from disaster.

AIDS is a major national crisis. As a nation, we have responded generously to the earthquake that struck San Francisco last October. Sixty-five people died in San Francisco and the property damage in the millions. In response, billions of dollars of Federal aid were made available almost immediately.

A similar disaster is now striking most of the Nation's major cities. Cities like Atlanta, Dallas, Boston, Los Angeles, Miami, New York simply do not have the resources to cope with the AIDS disaster on their own. The Federal Government must come to the rescue.

As a first step, the CARE bill will provide emergency relief to our cities hardest hit by AIDS. The bill will also help provide comprehensive care for all people with AIDS and HIV infection throughout the country.

The CARE bill will also allow people to receive treatment and care in their homes. That is so much more humane and less expensive than hospital care. More importantly, the CARE bill will help pay for crucial early treatment for AIDS and HIV disease. Right now, up to 1 million people urgently need early treatment.

Thanks to research, treatments now do exist for people who are HIV infected and have not yet developed any symptoms, but many people cannot pay for these treatments because they need our help. Without treatment, many of these people will become seriously ill in the next few years. Unless we act decisively we risk losing this precious chance to save lives. We need the resources now to provide those people with care.

Finally, support for treatment and care is important, but we must continue and strengthen our commitment to AIDS research to find effective treatments and a cure. Recently there have been charges that AIDS research has received more than its fair share of Federal funds. AIDS demands our urgent attention because it is an infectious illness, spreading rapidly and killing people in the prime of their lives. We don't want to take money away from research for cancer or heart disease or any other serious illness. We feel that our Nation can and should provide the necessary resources to fight all of those diseases. The health of our people must be a top priority.

We cannot let up on our efforts to fight AIDS. The struggle that lies ahead threatens to overwhelm us. The people on the front lines of this fight need our help urgently to save lives. We cannot let them down. We need their energy, their dedication, and their love in the dark days that lie ahead. Thank you.

Mrs. BOXER. Thank you very, very much, Elizabeth Taylor, for your very poignant and your to-the-point comments. I would like to introduce you first by way of a nod to a few people who walked in—Representatives Tony Beilenson, who represents your area in California; Jerry Huckaby, Dale Kildee, and Marcy Kaptur.

I want to explain to Members that due to Ms. Taylor's schedule, she will have to leave after we ask her some questions, then we will take testimony from our colleagues. I will lead it off. I don't want to put you on the spot with this question, so don't feel that you have to answer all the questions.

Ronald Reagan recently went on TV with a 30-second spot talking about the need for compassion, and many of us were very pleased because as we fought this fight we felt that he was a very late entry into the fight. If he were to ask your opinion on what else he could do at this time to help us with this disaster aid approach and early intervention, which is very important at this stage, how do you think that he could help us? How do you think that George Bush could help us with this battle?

Ms. TAYLOR. I think to address more directly the issue as it is, more honestly. It is wonderful that he is willing now to help for pediatric AIDS, but I think it would be more meaningful if people spoke out in their effort to fight AIDS and had no barriers.

It is almost as if there still lies that stigma attached to the homosexual community. It is like it is sad and tragic about children; that, we can talk about, but we still can't talk about homosexual AIDS, and I think it is mandatory that we face that AIDS touches not only children, unfortunate women and gay people and now the heterosexual community, everyone with AIDS is a fellow sufferer.

There shouldn't be any difference in our emotions or our feelings or our helping. We should help everyone because everyone, as a friend of yours said, is somebody's child.

Mrs. BOXER. Exactly; that was Elizabeth Glaser who said that who herself will be here, by the way, next week to discuss the pediatric AIDS issue.

Mr. Chairman, do you have any questions?

The CHAIRMAN. I really want to thank you, Mrs. Boxer. You have presented very moving testimony that I think makes the point in terms of the need to address this issue. Let me ask you, have you presented these arguments to the Administration?

Ms. TAYLOR. To whom?

The CHAIRNAN. To the Administration, Mr. Bush.

Ms. TAYLOR. Yes, I have. I spoke to Mrs. Bush yesterday, and she is very well-informed about AIDS, and she was very receptive and is more than willing to help.

The CHAIRMAN. Great. We will need their cooperation in terms of getting a bill through here and also having it signed by the President, so I am glad that you are working both fronts. Thank you very much for coming.

Ms. TAYLOR. Thank you.

Mrs. BOXER. Mr. Guarini, any questions for Elizabeth Taylor?

Mr. GUARINI. Just a simple statement, that your testimony is very clear, very direct, and we are so thankful for your gracious appearance. I think you very blatantly underscored the point that we do have to have a national comprehensive strategy if we are to lick this scourge we have in our country. I thank you.

Ms. TAYLOR. Thank you.

Mrs. BOXER. Thank you, Mr. Guarini. Mr. Huckaby?

Mr. HUCKABY. No questions.

Mrs. BOXER. Mr. Bielenson?

Mr. BIELENSON. Other than just to thank you very much and to tell you how grateful we are to you for having come here and testified, how grateful so very many people throughout the Nation are for the leading role you take in this most important issue.

Ms. TAYLOR. Thank you.

Mrs. BOXER. Mr. Kildee.

Mr. KILDEE. Again, just to thank Ms. Taylor for her very, very important leadership in this very, very important field. Thank you very much.

Mrs. BOXER. Mr. Bryant? Ms. Kaptur?

Ms. KAPTUR. Madam Chair, I would just like to thank the witness very much for appearing and to say that I would prefer that she be called the Founding National Chairwoman of the American Foundation for AIDS Research. The testimony may have been incorrectly typed, but to thank you on behalf of many of the Members here, as well as the Committee in general for again taking a lead on an issue that most of America is afraid of. Thank you for being here today.

Mrs. BOXER. I have just one last question, then we will let you go.

You have worked very hard today for AIDS. This is your second stop, I believe, having gone to the press conference this morning to stand by Senators Kennedy and Hatch. I think with a combination of Senators Kennedy and Hatch, we are on our way, and I understand Mr. Waxman is going to introduce the bill here.

We are all very excited about the prospects of such a bill. This is another tough question, and it revolves around the issue of just how much the private sector can do. You are working night and day to raise funds for AIDS research, and your organization is really in the front lines of the so-called thousand points of light. I guess my question is a leading one, a rhetorical one but after working for so long and raising funds, do you feel that the Federal Government can sit back at this level of assistance and let the private sector do the rest? Or, do you feel we need to really mobilize and get the kind of funding that we really——

Ms. TAYLOR. No, I think it is on such a horrendous grand scale now that only the Government can take care of the numbers. In the private sector we can help rapidly, perhaps more rapidly than the Government, but we can't raise the kind of figures that you are talking about here today. We can help morally, we can give compassion and love and care, which is as important as money, particularly in this illness, but money and lots of money is the only thing that is going to build centers, hospices, care units.

It takes volunteers to people those units, and there we can help, but it takes billions of dollars for research. We have raised $25 million for research, and that is a drop in the bucket, and of course the Government has to do more.

Mrs. BOXER. I am very glad that you put that on the record because I think that is an important argument that we will face as we go forward in this battle. Let me say on behalf of everyone, I think you have gotten the sense from all of us as to how grateful we are for your appearance here today.

This fight has sometimes been a very lonely one, and when you joined it, it gave us great heart and hope, so we couldn't be more delighted with your presence here today. We wish you well, and we will work together until we see that we get the impact aid and the early intervention that is so desperately needed. Thank you, very, very much.

We will just take a 2-minute break so Ms. Taylor can exit in a rather decent way.

[After recess.]

Mrs. BOXER. The Task Force is going to continue its hearing. We are very honored by the presence of several Members of Congress, one of whom serves on the Budget Committee, but is feeling so strongly about this particular issue that he asked if he could testify before us. I will lead it off with our committee member, Chuck Schumer.

STATEMENT OF HON. CHARLES E. SCHUMER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. SCHUMER. Thank you, Madam Chairwoman.

I appreciate the opportunity to testify and your holding these very important hearings. I will be very brief because I know you have a busy schedule. I am here just to talk about the AIDS hospital Medicaid initiative, which is part of the whole initiative that you and I and others are trying to move through the Budget Committee and then Henry Waxman will try to move it through the Commerce Committee.

This initiative is offered in tandem with Mr. Waxman, who has offered it as part of his AIDS proposals. The point, I guess, that I wish to make is that there are hospitals throughout the Nation that, just like other areas, face a state of emergency. They have large numbers of AIDS patients, and the impact, simply stated, upon them is devastating.

Treatment of AIDS patients, of course, directly impacts on the treatment of all patients, and it has direct implications for the allocations of hospital beds, staff, and equipment.

For example, we have all heard how crushing demand for hospital services has at times closed emergency rooms in vital hospitals for many hours and sometimes even days at a time. With projections of increasing numbers of AIDS patients, many hospitals face the grim prospect of simply being overwhelmed by AIDS.

In the Northeast the average public hospital loses over $600,000 a year in provisions in AIDS care. The average private hospital loses $200,000 in AIDS care, and if this Committee is going to ask many of our hospitals to cut back further because of changes in the Medicare and other reimbursement formulas, the least we can do is say to those hospitals that have a huge burden and are shouldering it willingly for people with AIDS, that they should get some kind of relief.

The AIDS patients are unfortunately concentrated in a relatively few major metropolitan areas, and you have about 3 percent of the Nation's hospitals treating 50 percent of the people with AIDS. Among the 25 hospitals with the greatest number of admissions nationwide in 1987 were Atlanta, Miami, Washington, DC, Baltimore, San Diego, Dallas, Houston, and Chicago.

This is not simply a problem that affects New York and San Francisco and Los Angeles, but a good number of the cities. The costs, as I know everyone knows, are astronomical—$681 a day. It is something we must do. The hospitals are doing it, but the Federal Government has some responsibility, and that is what the initiative is all about.

We establish a new payment to hospitals that care for an unusually large number of AIDS patients. Medicaid is primary payer for about 45 percent of all AIDS patient admissions only. Currently hospitals that care for a large number of Medicaid or no payment patients do receive an additional payment.

The initiative establishes for eligible hospitals a new payment per AIDS Medicaid patient in an amount no less than 25 percent to the per-patient Medicaid reimbursement. So I would ask that the Committee carefully consider this initiative which, I know that the gentleman from California, who just came in, and the Chairperson of these hearings, you, Mrs. Boxer, are actively supporting. Thank you for your time.

Mrs. BOXER. Thank you. Thank you very much, Mr. Schumer. We have put up there a chart that shows the cities that are most heavily impacted. You can see your very own New York on that chart, Mr. Schumer, followed by Los Angeles, San Francisco, Newark, Chicago, there is a whole group, Philadelphia, that are very heavily impacted.

I would ask you to join us up here if you wish, Mr. Schumer.

Mr. SCHUMER. It would be my pleasure.

Mrs. BOXER. That would be wonderful and would ask Ms. Pelosi——

Mr. SCHUMER. May I ask myself some questions?

Mrs. BOXER. The Chairman said you may not, but it is all right with me.

Ms. Pelosi, we welcome you to these hearings and ask you to testify either from your prepared text or extemporaneously, whichever pleases you.

STATEMENT OF HON. NANCY PELOSI, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Ms. PELOSI. Thank you very much, Madam Chairperson, and thank you for the opportunity to present my views on the Administration's 1981 proposed budget. I also appreciate all of your leadership on the issue of AIDS and on the calling everyone's attention to the need for impact aid which is the focus of today's hearing.

I am pleased that so many Members of the Task Force are present for this important testimony. I recognize the challenging task this Committee has before it in determining the spending priorities of our country, particularly our Chairman, Mr. Panetta, and appreciate both of your leadership and attention to the staggering problem of AIDS.

Madam Chair and Members of the Task Force, the Administration's 1981 AIDS budget demonstrates a lack, a major lack of understanding and leadership. It shrinks from the new challenges and retreats to old programs, which do not meet new needs.

As you are aware, the Administration is proposing that AIDS spending go from $1.53 to $1.69 billion for AIDS-related activities for the Public Health Service. This represents a real increase of only 2.4 percent, totally ignoring the increased case load.

Madam Chairman, Chairperson, I ask unanimous consent to submit for the record charts demonstrating the professional judgment request by an agency within the Public Health Service and how these needs assessments were ignored by OMB in reaching the final figures.

Mrs. BOXER. Without objection, they will be put in the record.

Ms. PELOSI. Thank you, Madam Chairman.

These estimates of need do not come from outside advocates. These requests come from the administration's own scientists, physicians, and public health experts. For all the public health service agencies, the professional judgment requests total $3.1 billion, or nearly twice the OMB figure of $1.69 billion.

Are we doing all we can as a nation to respond to the public health threat of the century? The answer, I think you will agree, is an emphatic no. The administration's budget indicates a willingness to do about half of what we can and should do.

In regard to a vaccine or cure, Dr. Fauci, who, as you know, heads the AIDS research efforts at NIH, is scheduled to rescind only 59 percent of what he requested to conduct AIDS-related research. Scientists tell us there are many new drugs worthy of clinical trials. The only limitation is the funding for this research.

The President's proposed budget means that plans to expand ongoing clinical trials and initiate new trials will be suspended. Ini-

tiatives for research centers, research training, drug development, and vaccine development will be suspended. Initiatives to give emphasis to underrepresented and minority groups will be suspended.

Are we doing all we can as a nation to prevent the further transmission of HIV? Again, the answer is, no. Federal and State prevention programs lack an emphasis on individual behavior change, the only way to stop the spread of the virus.

Demonstration outreach programs sponsored by the National Institute on Drug Abuse have clearly demonstrated that an aggressive outreach program can greatly reduce HIV transmission. The results from these 63 pilot programs across the country give us hope. Yet, this Bush budget proposes to zero out the program.

As incredible as it may seem, these outreach programs, which are literally holding back a new waive of HIV infection, are scheduled to be phased out with nothing proposed to replace them.

Are we doing enough to care for people with AIDS and HIV disease?

Again, the answer is, no, but even worse, Madam Chair, the Administration has decided as a matter of policy that the Public Health Service should not be involved in patient care, not even in this epidemic. This decision, in turn, has led to a major shift in priority which goes directly against logic regarding what needs to be done at this point in the epidemic.

It also runs against the direction strongly recommended by the National Commission on AIDS and the President's Commission on the HIV Epidemic, which preceded it. While the budget assumes an increase of 30 percent in a number of new AIDS cases, discretionary spending for AIDS-related patient care and services would be decreased by 35 percent.

The Health Resources and Services Administration, HRSA, requested $167 million for AIDS-related services. OMB gave them $33 million, or only 20 percent of their request. Entire programs for home health services and AIDS drug reimbursement for low income people were eliminated, entire programs for AIDS-related counseling and mental health services and for early intervention projects were eliminated.

Entire programs for sub-acute care, oral health care and health care planning were eliminated. These programs address the most pressing need at this point in the epidemic. I would like to emphasize that the Administration is not proposing to reduce the funding for these programs. They are proposing to eliminate them entirely.

The only clear policy to emerge from this budget is that the financing of health care is not a Federal responsibility. Clearly, Congress must assert that managing the cost associated with this epidemic must be a responsibility shared by all levels of government, local, state and federal.

Madam Chair, we were both present when Director Darman gave his very distressing testimony last year before the Government Operations Committee. Following his appearance, he asked to be judged on the fiscal year 1991 budget and not the budget he inherited from the Reagan Administration.

The new judgment is in. This is the worst AIDS budget in at least 5 years. It not only sets an arbitrary spending limit that is

unrealistic, it also goes to ideological extremes to eliminate programs that actually help people with AIDS.

It would shift funding from effective prevention programs to ones which do not work. It would suspend growth and research to find a cure. The administration has failed to send us a reasonable budget request. Congress must do better. The highest possible figure must be established for the health function so that the emerging priority issues, as you mentioned earlier, Madam Chairwoman, impact aid to hard-hit metropolitan areas and early intervention programs to treat people early in the disease process can be funded.

Cuts in spending for basic research and preventive efforts must be stopped.

Madam Chair, again, thank you for the opportunity to present my views on the President's proposed budget. I commend you and other members of the committee for all that you are doing to reassess the many pressing needs of our country. I wish you great success. Thank you, Madam Chair.

[The prepared statement of Ms. Pelosi, with charts, may be found at end of hearing.]

Mrs. BOXER. Thank you, Congresswoman.

Can you stay with us so we can hear from Mr. Waxman and then you can both respond? I just wanted to say what a pleasure it is to have you here. You speak directly, your facts are in order, and I think your message is clear.

Ms. PELOSI. Thank you, Madam Chair.

Mrs. BOXER. Mr. Waxman, we are delighted you are here. Please proceed as you feel most comfortable.

STATEMENT OF HON. HENRY A. WAXMAN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. WAXMAN. Thank you very much, Madam Chair, Members of the Budget Committee.

Let me begin by thanking you for holding this hearing. You have shown real leadership on the problem of the AIDS epidemic and what it poses to the nation. I hope this year's budget we can begin to address some of these issues that are most pressing.

Over the past 9 years, the country has gone through cycles of AIDS awareness, from ignorance to hysteria to complacency. We have gone from a time when no one knew of AIDS to a time when everyone was terrified of it, to a time when everyone knows about it and most people are seemingly unconcerned.

This complacency is dangerous for public health policy on infection and treatment. But such complacency is particularly dangerous for budget policy. We cannot shortchange the epidemic. It is threatening the lives of hundreds of thousands of Americans. It is threatening the solvency of our public hospital system. It is threatening the adequacy of health care services to all Americans, infected and uninfected.

The President's budget is constructed as if these costs won't happen, as if the worst of the epidemic is over. It is not. The worst is yet to come. This budget doesn't provide for those sensible activities which could help us reduce the spread, development, and impact of this disease.

There have been 120,000 cases of AIDS in the United States in the last 8 years, and the health care system in urban areas has been stretched to the breaking point. The Public Health Service estimates that there are 1 million infected Americans, and that more than half of them have severely compromised immune systems already.

Over the past 2 years, the major research advances in AIDS have been the development of drugs that will prevent or slow the development of an HIV infection into diseases that require hospitalization. With such treatment, people live longer, healthier, more productive lives. And hospitals have fewer patients and medicaid fewer costs.

Right now, however, although poor people with full-blown AIDS can qualify for Medicaid assistance, poor people who are infected and have a deteriorating immune system—but who don't yet have full-blown AIDS—cannot. That means that Medicaid will pay when people need expensive inpatient care to treat pneumonia but won't pay when they need drugs to prevent pneumonia.

It is a crazy Catch-22 for Medicaid and for the patient. Rather than keep people productive, we let them deteriorate. That's stupid, and it is expensive. In addition to addressing this Catch-22 early intervention, we must also turn our attention to the hospitals that are caring for AIDS patients. Congressman Schumer has addressed that. Inner-city hospitals are overflowing now. Public hospitals are on the edge now. Without some help, they will be bankrupt.

But Medicaid does not begin to pay for the real costs of the epidemic to the hospitals that are treating AIDS patients. While every institution expects the average Medicaid patient to cost it money, aids patients cost them a lot of money. According to a 1987 survey, hospitals lost an average of $136 per day under Medicaid on AIDS patients. This is about five times the average loss that hospitals reported that year under Medicaid on their average medical/surgical patient.

These are not hospitals that can easily make up losses on Medicaid patients by raising charges to private patients. And these are not hospitals that these communities can afford to lose. While Medicaid may not be able to do much to improve the situation of these hospitals, we can't allow inadequate Medicaid payments to make their problems worse.

In addition to these Medicaid improvements, we must also pursue discretionary spending to provide emergency assistance to some areas of the Nation that are hardest hit by the epidemic's past 9 years and will be even more stretched to meet the demands of the coming cases.

It is becoming clear, however, that many of these voluntary agencies are not able to cope with the scale of the epidemic in the 1990's. Finally, we must pursue a large-scale program of prevention: Prevention of infection among the uninfected and prevention of disease among those already infected. Such a program involves Federal grants to States and clinics for counseling, testing, diagnostics, and early intervention drugs.

Along with many Members of this Committee I have introduced H.R. 4080, the Medicaid AIDS and HIV amendments to make early

intervention drugs available and to effect hospital payment changes in Medicaid. I will also be introducing other legislation on AIDS prevention and emergency assistance.

Clearly, there is much more that we must do, and I know, Madam Chairwoman and Mr. Panetta and Members of the Budget Committee, with the kind of deficits that we have, you would rather not have us come here and press you for more Medicaid spending, more discretionary spending to deal with the AIDS problem.

We really have no choice. Unless we pay for the early intervention drugs for Medicaid patients, we are clearly going to pay through Medicaid for their hospitalization. Unless we give a higher reimbursement to those hospitals that take care of Medicaid patients, we are going to lose those hospitals.

There is no other way around this because Medicaid is becoming the payer for health care services for AIDS patients, especially as they lose their private insurance. We are also trying to make available through Medicaid the opportunity for States to use Medicaid to help pay for the covert extension of health insurance that will bring the gap between those who lose their insurance to the time when they are so disabled that they end up on Medicare if they can live that long, but Medicaid, according to many States, should be available to them at their option to cover the care for those patients that would otherwise lose their insurance in its entirety.

We are going to need Medicaid money. We are going to need discretionary spending, and the discretionary spending for emergency care for those areas hard hit, we are going to need discretionary money for a bill that we are working on and soon will introduce for testing, counsel, and early intervention drugs.

We are going to need more money as well for research. We must make a start. If we don't, our whole public health care system may be flooded with sickness, death, and bad debt. The communities it serves will be devastated. The enormity of the problem is only dawning on most people now, many of whom thought the epidemic was waning.

The President's budget does not begin to meet the needs. This Committee must do so. Thank you for this chance to testify.

[The prepared statement of Mr. Waxman may be found at end of hearing.]

Mrs. BOXER. Thank you very much. I would say that our two witnesses really have been on the cutting edge of these issues. Ever since I came to Congress, Congressman Waxman was right there in the leadership, and since Congresswoman Pelosi arrived with fresh energy, she has really led the way.

I think it is very interesting, both of your testimonies side by side just go hand in glove because what Congresswoman Pelosi did was show us the shortcomings in the Bush budget and you, Mr. Waxman, kind of give direction as to what we can do specifically. I don't think you collaborated, but you have presented us with an excellent comprehensive view.

I would like just to place Mr. Weiss' testimony into the record so it can follow immediately after these.

[The prepared statement of Mr. Weiss may be found at end of hearing.]

Mrs. BOXER. Mr. Waxman, give us an example of how the system is failing, a case that comes into a heavily impacted hospital, how that hospital loses the dollars. If you can, just bring it down to a case-specific basis for us.

Mr. WAXMAN. A patient has AIDS and requires hospitalization. We weren't fortunate enough to reach that patient to discover the infection before the infection developed AIDS and use some of these early intervention drugs. The patient requiring hospitalization goes to a hospital.

If that patient does have private insurance he is going to go to a hospital that will take him. He is covered under Medicaid because he is disabled. By the way, if he were only infected and were poor, he wouldn't get help from Medicaid for those drugs because he is not disabled, because the tie-in is you are either aged, blind, disabled, or children, not just poor. Poor doesn't do it.

The Medicaid law says he is disabled. He is clearly disabled if he has AIDS and requires hospitalization. Now Medicaid will pay the bill. He will go to a hospital that will take Medicaid patients. Medicaid will pay the hospital much less than it costs the hospital to care for that patient.

What are the hospitals that take these kind of patients? Well, they are most likely public hospitals or hospitals with a tremendous amount of low income patient populations, not just AIDS, but poor people with other medical problems also being reimbursed by Medicaid, also being reimbursed less than what the cost is to the hospital.

Hospitals that have a high share of low income patients don't have the ability to shift some of the costs that are not met by Medicaid on to private pay patients or privately insured patients because by and large they don't have privately insured patients, so the hospitals are hanging on, hoping that they can shift things back and forth to the point where at some clearly discernible event they are going to find that they are just running out of money to take care of any of the patients, and that is the case with many urban hospitals that are wondering whether they can even keep their doors open to anyone.

Mrs. BOXER. So, the population in these hospitals is such that they just don't pay their way, and they can't shift to the people who have insurance because those people aren't at those hospitals? Have you discussed the problem of these hospitals with Mr. Stark?

Mr. WAXMAN. I haven't discussed it with him, but these wouldn't be Medicare patients. These are—until 36 months after they are hit with AIDS, would they then be eligible to be on Medicare SSI.

Mrs. BOXER. As opposed to Medicaid.

Mr. WAXMAN. For the most part these patients haven't lived long enough to get Medicare, so they are on Medicaid. I am happy to talk to Mr. Stark and others, but Mr. Dingell has the jurisdiction over the Medicaid area in our committee.

Mrs. BOXER. So the Medicare doesn't begin until 36 months?

Mr. WAXMAN. But Medicare becomes the payer once the patient is disabled. Our committee, which has jurisdiction over Medicaid, can't move unless your committee provides the funds that will allow us to pay for early intervention drugs, pay a higher reimbursement rate to those hospitals that take Medicaid patients, and

thirdly allow the States at their option to use Medicaid dollars to cover people to have their private insurance available to them.

Mrs. BOXER. The reason I mentioned our colleague, Mr. Stark, who is a dear friend of both of ours, is that I am concerned about his feelings about hospitals today, and I think it is important that we make the point that there are some hospitals that are in serious trouble. That was my point.

Mr. WAXMAN. It is a good point. He is mindful of it because in the Medicare program we have tried to have a higher reimbursement for Medicare patients for those hospitals that have a higher disproportionate share of low income Medicare cases, so on Medicare we try to give a little higher reimbursement.

On Medicaid many of those hospitals don't even have that much Medicare. On Medicaid, they are even in dire straits.

Mrs. BOXER. Ms. Pelosi, I have one quick question for you, then I will turn it over to my colleagues.

In San Francisco we have what is known as a San Francisco model. We have been able to do some very cost-effective things to avoid the high cost of hospitalization. Are we at a crisis point now in San Francisco? In other words, can we continue this if we don't get impact aid, in your opinion?

Ms. PELOSI. No, I do not, Madam Chair. San Francisco has been a model of how to treat AIDS patients. That is, maybe a person with AIDS shouldn't be in the hospital, and we would like to make that person as comfortable as possible at home or whatever. So we have striven for what is best for the patient and what is best for the budget, and frequently they are the same thing. People do not have to pay the high cost of going to the hospital just because they have AIDS. In fact, there is legislation pending for this consortium approach to caring for people with AIDS. But frankly, many of our people are burning out.

This issue has been with us for a while in San Francisco. The number of people in the gay community becoming infected with HIV has been curtailed. But the people who have, HIV, who are now contracting opportunistic diseases associated with the HIV, that caseload is increasing, and we simply do not have the private resources to continue to deal with the number of cases at hand. So we will absolutely need some Federal participation, as you mentioned, the impact aid, as Chairman Waxman and you have both mentioned, the early intervention is very important to us, but impact aid is something that we are looking to with hope. It is in the interest of the U.S. taxpayer as well as in the interest of people with AIDS.

Mrs. BOXER. Mr. Chairman.

The CHAIRMAN. Thank you very much, Mrs. Boxer.

Thanks to both of you for the testimony you have provided. As always, it is a very important issue for us to confront, and when the Administration doesn't put a lot of money into it, then the pressure comes on us to try to face up to that responsibility.

I recognize the leadership that both of you have provided on this issue. One of the criticisms that I have heard is that doubling the amount of money, not on the Medicaid issue, Mr. Waxman, but on the other side, that would flow to the Public Health Service and research, is questionable. I have been told that because of the lack

of resources in place, the lack of personnel there, the lack of adequate scientists, researchers, et cetera, that even if you doubled the money it is not going to be used effectively.

I guess I would be interested in your comment on that. The Appropriations Committee provided about $1.6 billion for AIDS in fiscal year 1990. Is that being effectively used right now, and if we double that number would it be used effectively by the Public Health Service?

Mr. WAXMAN. Mrs. Pelosi contacted the researchers and asked them what they thought they needed, and they indicated this money could be needed and used constructively. The question of resources, when we have a ceiling on full-time equivalent employees at NIH becomes a difficult one, and I think we need to eliminate that ceiling so we can use that money effectively.

If we do eliminate that ceiling, that money can be used for research, and I take at face value the comments of the researchers as to what they think they need.

Ms. PELOSI. May I address that, Mr. Chairman, for a moment?

Last year when Mr. Darman was in front of our Government Operations Committee, I asked him the question, Who are the scientists at OMB who are second-guessing the Administration's own scientists, doctors, and public health professionals? Who down there at OMB knows more about what is necessary in the fight against AIDS than the Administration's own medical professionals? What gives you the justification to cut these requests?

He said two things. He said, first, it wasn't his budget. It was the Reagan budget; give him a chance. But more to the point, he said, oh, everybody knows that agencies pad their requests. They know they are going to get cut back. Then I called some of the scientists after that hearing and specifically spoke to Dr. Fauci at some length then and since then.

Basically what the scientists are telling us is that, quite to the contrary, they are not padding their budgets knowing they are going to get cut back. Because of what Ms. Taylor testified to and what Mr. Waxman referred to earlier, the competition for the dollar in biomedical research many agency heads are giving their most responsible, defensible number.

They need more, but if they ask for as much as they think they really need, then there might be some reaction to that request, so they have given realistic figures which are in no way padded, but below which would be irresponsible to ask for.

That is what I heard from the scientists. So as far as I can tell from Mr. Darman, there are no scientists at OMB better qualified to determine the needs for AIDS than the scientists in the Administration.

Mrs. BOXER. Thank you very much.

We appreciate, again, both of your testimonies. You can be assured that the committee will respond to this issue.

Thank you, Mr. Chairman. With the indulgence of the Task Force, if you could hold off on questions, Mayor Dinkins has arrived along with Mr. Weiss. I would like to thank Mr. Waxman and Ms. Pelosi, of course, for their leadership. We will work very closely with you. You will be called on, and we will do the very best we can to meet all of the needs that you have outlined, and I

certainly share and would associate myself with your requests. Thank you very much. We will bring in Mayor Dinkins.

I will also ask the second panel on impact aid to take their seats, Mr. Sweeney, Dr. June Osborn, if you would take your seats up at the witness table, and then you will be joined by Mr. Dinkins and Mr. Weiss.

We are just delighted, Mr. Mayor, that you are with us. I am going to ask Congressman Chuck Schumer to have the pleasure of introducing you formally.

Mr. SCHUMER. Thank you very much, Madam Chairman.

It is my pleasure to be here and to introduce our next witness, Mayor David Dinkins of New York City. Mayor Dinkins really doesn't, even though he has only been in office 2 months really doesn't need an introduction to this Committee and to the community in Washington DC because he has already established himself as a leader, as someone who is willing to speak out for our Nation's cities and people who need help, poor people and others, and he has done it in a way that I think has really caught the Nation's attention.

When he ran for mayor, his slogan or one of the slogans on the literature that I gave out said you don't have to be loud to be tough or something to that effect. I may have it a little bit wrong, but it was something to that effect. Mayor Dinkins has already proven that down here in Washington. He speaks with a civility and a gentleness, but he speaks with a firmness and a toughness that comes uniquely to him and because of the problems that the city has.

Furthermore, aside from making a great start at being mayor of what is often said to be the second toughest job in America, I really think it is the toughest job in America, not the second toughest. But in any case, the Mayor, on this issue has been an advocate long before he was mayor, as bureau president of Manhattan and early on in his career, Mayor Dinkins was perhaps the leading voice in the city of New York talking about the problems that people with AIDS have and in terms of the needs of the city, State, and Federal governments to come to their aid.

I need not tell you how much the city of New York is doing for people with AIDS. We are doing a whole lot, but without Federal help, given the budget crisis that we have, we can't do that much more, and for that reason it is really my pleasure to introduce to all the Members of this Task Force someone who everyone from one end of our great city to the other respects and is delighted is our mayor, David Dinkins.

Mrs. BOXER. Thank you very much, Mr. Schumer.

Mr. Mayor, if you look at that chart, the blue chart there, the bar at the very bottom represents the number of cases in New York, you can see how your city fares. It has the leading number of cases. I know that you are aware of it, but when you see it as starkly as that chart, I think we all recognize the problem that you face, and that is why we couldn't be more pleased that you are here.

You are actually in the front lines on this, along with Mr. Schumer, who is carrying a very important initiative on this. We welcome you here. We know your schedule is tight, so as soon as you

finish, we will ask you whatever questions we have and then you will be free to go on to your next appointment. Welcome, Mr. Dinkins.

STATEMENT OF HON. DAVID DINKINS, MAYOR OF NEW YORK CITY

Mr. DINKINS. Thank you very much. You are very kind. Chuck Schumer, an old friend, I thank you for that more than generous introduction.

I am delighted to be at the same table with Dr. Osborn. We were together earlier today; my long time friend, Ted Weiss, and Tim Sweeney, with whom I have a long and friendly relationship. I am so pleased that we are here together. I thank you, Madam Chairwoman, for providing me the opportunity to testify here today and for your continued leadership in fighting the AIDS epidemic. I know that you are an ex-New Yorker, and I am sure you will agree that once you love New York, you always love New York.

I know that you are aware of the damage the AIDS epidemic has caused, but you may not know the extent of that damage. Let me state the scope of this situation clearly for all of the Members here today. In New York City, according to the most recent estimates by our Department of Health, 235,000 people are carrying the HIV virus—235,000 people.

To put that into perspective, think of your own districts and imagine that nearly half of your constituents are HIV positive. Not half of your voting constituents, not half of your adult constituents, but half of all the people who live in your district, men, women, and children of all races and all classes, infected by a virus for which there is no known cure. That is why we need your help.

Despite all of our efforts at prevention and education and despite all of the private efforts as well, especially in the gay community which has organized education and treatment efforts in a heroic fashion, this virus is spreading.

We expect the epidemic to continue. We expect the dying to continue, and we expect the extreme pressures on our health care system to continue and to grow, and I know that all of you know that while we in New York may have been hit first and worst, we are not alone.

Before I describe the type of assistance we need and the legislation that will help meet our needs, let me first directly dispel a misconception that I think is still far too prevalent in this society, a misconception that if we are honest with each other we will admit cause many to react far too slowly to this epidemic.

AIDS is not a gay disease. This is no gay plague, no group and no community is immune, and the myths and stereotypes to the extent that they persist are killing people by killing the national resolve to confront this public health challenge in a reasonable and responsible way.

Our enemy is the HIV virus, not those who carry it. Our enemy is the inattention and lack of compassion that for too long have fueled this epidemic, and our enemy is our own inability to organize our health care system to provide for those who are most vul-

nerable and who have the least access to decent and affordable assistance.

Consider these facts and the picture they paint of the needs of our health care system. AIDS has literally become a public health disaster for all communities and all constituencies in New York. It is the third leading cause of death in our town, right behind heart disease and cancer.

It is a leading cause of death among men aged 30 to 44, among women aged 25 to 39, and worst of all, among children ages 1 to 4, and African Americans and Latinos now constitute 61 percent of all new adult cases of AIDS, 84 percent of the cases among adult women and 91 percent of the AIDS cases among children.

Let us look at those children with AIDS, the ones who will never know what it is like to live and to love as adults, free of disease and despair. In case after case their mothers were either IV drug users or the sex partners of IV drug users; thus what has become perfectly clear is that we are fighting a dual epidemic now, drugs and AIDS.

Current estimates show that as many as 90,000 drug using males and 30,000 drug using females in New York City are infected with the HIV virus. That represents fully 60 percent of an estimated total of 200,000 IV drug users in New York City.

All recent studies indicate that HIV infection is spreading within the population of intravenous drug users in New York City. In fact, of those interesting drug treatment programs, it is reported that about 60 percent are already infected with the virus, but the twin epidemics of drugs and AIDS have not so much created a crisis as exposed chronic weaknesses and structural defects in our health care system.

We have made a decision in this Nation to pay for medical care on the cheap, by, among other things, not letting certain people have access to care, thus the poorest and the sickest are the most likely to go untreated because they are uninsured, and these epidemics are the price we are paying for that decision.

In New York State, for example, 2.5 million people are officially listed as being medically uninsured, though if we were to count New Yorkers insured for only part of the year and not insured for the rest, the figure would be much higher.

Of that 2.5 million, about one-third are under 18 years of age; 23 percent are Latinos; 19 percent are African Americans and when it comes to AIDS, who are the most vulnerable of the most vulnerable? Young African Americans and Latinos. That is not a coincidence. It is a disgrace. We are doing a great deal in New York City on our own to confront these twin challenges.

We are in the midst of extremely tough fiscal times. The declining national and regional economies that have caused substantial revenue shortfalls in half the States have caused us in New York City to propose significant reductions in public services. An increase in the property tax and the surcharge on the municipal personal income tax, clearly these are difficult fiscal conditions, yet despite our budget woes we are maintaining, and in some situations embracing our local commitment to fighting AIDS and drug abuse.

We have cut sanitation services, fire protection, parks maintenance, some school programs, and we have even deferred the hiring of police officers, but we have not cut our local commitment to drug treatment because we know that if we do not deal with drug abuse now, we will have more addiction, more crime, and more AIDS later.

At the same time, in the midst of the worst fiscal crunch in 15 years, our city is spending $271 million of our own tax levied funds in our efforts against AIDS. Our commitment is clear. Our determination is demonstrated, yet our needs continue to grow. The Comprehensive AIDS Resources Emergency Act of 1980 introduced today in the Senate by Senators Kennedy and Hatch offers us part of the help we need. And I urge all of you to work for its prompt passage. This legislation will provide emergency relief to those metropolitan areas hardest hit by the AIDS public health disaster, and that by itself would be significant and welcome, but this legislation will do so much more. First, it will provide assistance to hard-hit communities, such as New York, not only for hospital care, but also for home care, hospice care, and community-based outpatient services that are both more humane and cost-effective.

Second, the Kennedy-Hatch bill will fill glaring gaps in the health care system for people with AIDS to assure continued insurance coverage for people with HIV disease, and, third, this legislation recognizes the reality of caring for persons with AIDS by authorizing funding for creating and operating local public and private health and support service entities.

These service providers will be capable of delivering a comprehensive continuum of care with the operation of other community organizations which have a demonstrated history of providing services to people with AIDS. So this bill embraces the right approach at the right time.

It recognizes that community-based care is the best approach and that organizations with experience in caring for people with AIDS are the best providers. It acknowledges that greater access to care is often the principal need and the protection of health insurance for people with AIDS often is a fundamental requirement.

Most of all, this bill is based upon the understanding that this is a national epidemic and a national challenge, but that the greatest need for overall assistance is found in those metropolitan areas that have been hardest hit.

I thank you for listening, and I thank you for caring. I hope you will appreciate the urgency of this epidemic and that you will act expeditiously in providing the assistance required to respond to this disease. Thank you.

Mrs. BOXER. Mr. Mayor, we thank you. You have heard the bells. Your timing was excellent. That means we have to vote, so we do have about 12 more minutes left. What I would like to do is just tell you that your comments are right on target as for what we are about to do here, which is to take the President's budget and look it over and see where it is wanting. And many of us do believe it is wanting, and will work with you to see that that AIDS budget number comes up higher.

I would like to ask Mr. Panetta and Mr. Schumer if they would like to thank Mr. Dinkins and then I will discuss with Mr. Weiss if

he would like to make a quick summary of his statement or if he wants to come back.

Okay, he will come back.

The CHAIRMAN. Mr. Mayor, we welcome you to the Budget Committee. As you may or may not know, in one of my past lives I used to be an executive assistant to the mayor in New York City, so I know some of the challenges that you are facing. We are very proud of your election, very proud of your leadership in New York, and very proud of the leadership that you are providing on this issue. Thank you for your testimony.

Mr. DINKINS. Thank you, sir, thank you very much.

Mrs. BOXER. Mr. Schumer.

Mr. SCHUMER. I think I have said what I have to say. This is the third time I am seeing the Mayor on three different issue: Census, clean air, and now AIDS, so it has been a very busy and hopefully will be a productive day that some of us here in Washington can get done some of the things that our city needs. Thank you very much.

Mrs. BOXER. Mr. Guarini, would you like to add a comment?

Mr. GUARINI. I would just like to thank the Mayor. It is good to see you again. Thank you for being so outspoken on all of the national issues that are so important to us.

Mr. DINKINS. Thank you.

Mrs. BOXER. Mr. Houghton, as a New York Stater, do you have anything to say?

Mr. HOUGHTON. No.

Mrs. BOXER. Mr. Kildee?

Mr. KILDEE. Thank you.

Mrs. BOXER. We all thank you very much. I know it has been a very tough day. We wish you the best. Thank you very much, Mr. Mayor.

The Task Force stands in recess for just about 15 minutes. We will come back as soon as the votes are over.

[After recess.]

Mrs. BOXER. The Task Force will reconvene.

We are very pleased that Hon. Ted Weiss has joined us. I would ask him if he is prepared at this time to speak extemporaneously or from his materials. We have, in fact, put your statement into the record immediately following Mr. Waxman's, so you are in the record as we speak, but if you would like to speak to us, we would be very happy to accept your testimony.

STATEMENT OF HON. TED WEISS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. WEISS. Good; thank you very much. Let me first of all express my appreciation to you for allowing me to testify before the Task Force. I would also like to commend and compliment you for holding these hearings at the earliest stage of the budget process because, if you don't provide adequate funding in the budget, the opportunity for adequate appropriations is lost. So this really is the most critical stage of the proceedings.

I know that you have received significant testimony already and will be receiving even more, so I will not read my prepared statement.

The AIDS epidemic is increasing steadily as we sit and we talk here today. The most urgent task we face right now is providing care to all those who are becoming infected and sick. But that is all we are doing; we are sitting and talking. The former Surgeon General, Dr. Koop, said last month that we have an epidemic that is 9 years in the making, but we are 9 years behind in having a national plan for dealing with care and treatment for AIDS. The Federal Government still doesn't have a plan or a program. There has been no national executive leadership, and we need it desperately.

Nothing is clearer than the budget that has been submitted by the Administration. I have in my prepared testimony a list of areas where the whole process of providing care has been shortchanged. Most significantly, our numbers are based on those of the health professionals in the agencies within the Public Health Service who have always been responsible and conservative and have asked the Administration to request $3.1 billion for AIDS programs—which would barely meet the needs that are out there.

Instead, the President has submitted a budgetary request for $1.7 billion. That shortfall of $1.4 billion is going to be taken out of the very lives of the people who develop AIDS and who will not have the treatment and care facilities or the professionals to care for them, and so I am hopeful that in analyzing the Public Health Service professionals' request, that you will agree with them and provide an amount within the budget resolution that will meet their minimal needs, as they see them.

Again, Mrs. Boxer, I want to thank you very much for the tremendous work that you and the Task Force are doing in this regard, and for the opportunity to appear before you today.

Mrs. Boxer. Thank you, Mr. Weiss. I, of course, want to say that your leadership on Government Operations is really legend. You carry this fight to every corner of the country, and we work very closely together and will continue to do so.

I think the testimony that you submitted, as well as your remarks, the testimony of Ms. Pelosi and of Mr. Waxman really weave together a very clear path for what we have to do. I am going to take those recommendations to the task force and to the full Budget Committee, and with your help we can at least come out of this first gate with a number that gets us where we need to go because, you are right, if we don't do it here, the chances of money being added on are just quite minimal.

So we really thank you.

Mr. Weiss. Thank you very much. If you will excuse me, I will now attend to some other things.

Mrs. Boxer. Indeed, Mr. Weiss. We are glad you finally made it from New York.

Our other members of the panel, Tim Sweeney, Deputy Executive Director for Policy, the Gay Men's Health Crisis and Dr. June Osborn, Chair of the National AIDS Commission, either of you may begin, whoever is prepared.

Mr. Sweeney, why don't you lead it off since you are first on the panel.

STATEMENT OF TIMOTHY J. SWEENEY, DEPUTY EXECUTIVE DIRECTOR FOR POLICY, GAY MEN'S HEALTH CRISIS, NEW YORK

Mr. SWEENEY. Thank you very much. I am the deputy director for——

Mrs. BOXER. Mr. Sweeney, do you have a statement you would like to put in the record?

Mr. SWEENEY. Yes, I do. I believe you received copies of it.

Mrs. BOXER. We will put that in the record. Feel free to summarize, but because of the time we would like to keep your summary at 5 to 7 minutes, if you could so.

Mr. SWEENEY. I am the deputy executive director for policy at the Gay Men's Health Crisis in New York. GMHC is the Nation's oldest and largest community-based AIDS service, education, and advocacy organization. GMHR has served directly over 8,500 people with AIDS. We have answered 300,000 calls for information on our hotline and we have distributed over 3 million pieces of life-saving information.

We have trained thousands of health and mental health providers. The vast majority of our work has been done by volunteers who currently number 1,700 volunteers, putting in 10,000 hours of time every month. I speak to you today as a representative of the thousands of community-based AIDS organizations providing psycho-social support, counseling, case management, food programs, and legal and financial advocacy to the HIV ill and their families, and prevention education and medical information to the general public and targeted populations.

My basic line is to tell you that while we are full believers in a private-public partnership on AIDS in the Nation's war against AIDS, the voluntary sector has been carrying a disproportionate burden in that war. For instance, at Gay Men's Health Crisis over 75 percent of our budget right now is privately raised. We are falling farther and farther behind in our ability to deliver the services to the people who need them.

We are losing our battle and our war against AIDS. Our caseloads are increasing at a rate far outpacing our funding. In New York City, for instance, the caseload is expected to increase from 22,000 AIDS cases reported by the end of 1989 to 33,000 by the end of this year. This is a 50-percent increase in this year alone which we as community-based organizations are supposed to deal with. While today GMHC has 2,800 clients, a year from now we will have 4,000. We truly don't know how we are going to meet their needs.

Community-based organizations in many ways are the Nation's front line troops in our war against AIDS. We have the credibility and the expertise to take messages on sexuality and drug use to the people who most need them, the people at risk. However, we don't have the ammunition to win our battles. We need large-scale Federal assistance in the form of emergency relief. The programs at HRSA must be expanded immediately. The Public Health Service must recognize that it, too, shares in the responsibility for care. This will bring to all of our local efforts immediate financial assistance, but especially those in the hardest hit cities. HIV positive individuals, our families and community-based organizations intend to be extremely active and vigilant participants in the local plan-

ning efforts and councils to determine program priorities for this funding.

With increasingly helpful therapeutic developments, we are reaching many more individuals and families who want services, but the sad fact is that while we have begun to see the results of our billion dollar investment in biomedical research, those therapies are out of the financial reach of the vast majority of people who need them.

In addition, as AIDS education and outreach expands, and it must expand much more, individuals and families at risk are stepping forward to be voluntarily tested. For those who are finding out they are positive, we must begin the intake and referral process. I just want to paint a little bit of some of the problems that we see now as an agency.

In August and September of this last year, GMHC's hotline was receiving 38 and 40 percent increases in calls. We handle about 5,000 calls every single month. Most of those callers had heard through the media about promising developments and wanted information on testing, AZT, and where to find medical care. There were few places we could send them. The frustrating and angering truth is that many of these callers do not have insurance and cannot afford a private doctor. Our local community health clinic was so overwhelmed by requests for help that they closed their waiting lists for 2 months. They are caring for over 1,400 HIV ill individuals with just two doctors. Our local self-help counseling group for HIV positive individuals, Body Positive, has a counseling group made up of male drug users who want to get into treatment, but are on waiting lists.

Thousands of people in New York City are on waiting lists for residential drug treatment programs. They must wait weeks and many times months. For those who do get ill and enter our hospital system, we have other barriers that confront them.

GMHC's ombudsman office constantly investigates complaints of people with AIDS waiting days in emergency rooms for a hospital bed. Both in the public and voluntary systems, critically ill people can wait as long as 8 and 10 days for a hospital bed. This last December, two GMHC clients died in the emergency room in a voluntary hospital while waiting for a bed. One waited 8 days, the other waited 9 days.

And we know in New York City we are at the very tip of an iceberg. According to the New York City Citizens Commission on AIDS, up to 225,000 New Yorkers are HIV positive. According to the New York City Department of Health, 117,000 New Yorkers who are HIV positive have a T-cell count below 500.

With the latest recommendation from the Secretary of Health, those 117,000 individuals should be receiving medical care in an early intervention program. The Secretary's recent recommendations mean that the number of people who should be receiving services increased tenfold.

We know what we need to care for these individuals. The HSA New York Task Force on AIDS says we need the following just for these limited categories. I paint this picture basically to dramatize how much this money is important to a city like New York. For acute care beds, by 1993 we will need 4,020. These are more beds.

For housing units, we need 2,640 units. For health-related facility beds, we need 590, for skilled nursing facility beds we need 630. For home care, the average daily enrollment will be well over 3,450. Physician visits alone will total over 1 million. We have also done some cost estimates on these.

The cumulative costs for providing such services through 1993 are also projected. For the acute beds it will be well over $4 billion, $4,409,000; For the housing units, $233 million; for health-related facility beds, $130 million; for skilled nursing facility beds, $235 million; for home care, well over $634 million; and for the physicians visits, $490 million.

I would just emphasize that these numbers, which total over $7 billion needed over the next 4 years now do not take into account substance abuse treatment, counseling, and prevention education programs, so this $7 billion is just for these six categories that I mentioned.

Increased Federal aid will help us stave off disaster in New York City. I don't think the New York Times was exaggerating when it said New York is in danger of becoming another Calcutta. As I sit before you today here, 15 more individuals, men, women, and children in New York City are diagnosed with AIDS today. Four of those people have come to my agency, GMHC, asking for help. We must have a new and renewed national effort to provide leadership and resources to win our war against AIDS. If I could ask just to back up my testimony, I have the report from the HSA Task Force on AIDS from July of 1989, if it could be submitted into the record.

Mrs. BOXER. Without objection, it will be done.

[At time of printing the document had not been received.]

Mr. SWEENEY. I would also like to submit the agenda developed for new funding for community-based HIV services. This is done by 27 community-based organizations in a coalition in New York City. I would like that submitted for the record, too.

Mrs. BOXER. Thank you very much.

[At time of printing the document had not been received.]

Mrs. BOXER. I will hold off on my questions until we hear from Dr. Osborn.

STATEMENT OF JUNE E. OSBORN, M.D., CHAIR, NATIONAL COMMISSION ON AIDS

Dr. OSBORN. Good afternoon, Congresswoman Boxer. Thank you for letting me have some time today.

I am, as you know, Dean of the School of Public Health at the University of Michigan and also Chairman of the National Commission on AIDS. I want to tell you about some of the experiences that the Commissioners have had recently that intensifies our sense of urgency about meeting health care needs of people living with HIV and AIDS. All these impressions lead to the same conclusion: That over the past decade, the United States has suffered the accelerating emergence of a human disaster that is unequally distributed across the country, that dwarfs in scale the physical disasters of recent times, and that begs for an urgent Federal response such as that embodied in impact aid.

Since the beginning of January, the Commission has visited some of the areas most severely affected by the first decade of AIDS, including southern California, New York and New Jersey. Furthermore, as chairman, I joined Mayor Agnos of San Francisco in January to help make public the product of a year's work by his AIDS Task Force, an event I will mention at the close of my remarks.

Let me share with you some impressions of the New York-New Jersey visit of last week, since they are indelibly etched in my mind. Parenthetically, a number of the Commissioners have told me that they, too, have found it impossible to shake the effects of what we saw when we visited there, and have barely been able to sleep since our visits with the homeless of New York.

The anguish we witnessed—the destitution, the unthinkable daily jeopardy of persons who lack homes and food and health care, whose families have been decimated by poverty and chemical dependency, and whose lives are now under threat from HIV and AIDS—all those abstract components of tragedy took human shape in the narratives of personal experience, and were made all the more real to us by the poignant pleas for understanding by the homeless people we talked with. The brave advocates and outreach workers who facilitated our meetings left me in awe of the courage they display just in returning, day after day, to a battle where they have no ammunition and, indeed, no battlefield on which to stand.

Images of our visit to the Fort Washington shelter are burned as indelibly on my retinae as if I had stared into the cruel winter sun. Nightly, 933 men sleep there—a slightly different group each night, depending on who is lucky enough to line up in time for a cot. The very great likelihood is that a majority of those huddled there—when we visited on the coldest night of the year—were infected with the human immunodeficiency virus. As a physician, I found that almost beyond contemplation. That should definitely be against medical advice.

But even in that unthinkable place, humanity shone through from what seemed the least likely of directions. A couple of destitute homeless men, showing their positive tuberculin skin tests to the commissioners, voiced their concern that, "People who are extra-susceptible to infections should never be sleeping in a place like this."

Fort Washington was not the only horror. During our travels we heard about families not only broken but kept asunder by rigid visitation rules for addicted mothers, even those under treatment. We heard from people who had at least staked out a specific shelter site, who were suddenly being shuttled from one remote cot to another, coincident with authorities learning of their HIV-positive status. Outreach workers told us of the extraordinarily brisk response of addicts to take up the hope offered by new drug treatment slots, and of the anxiety of the conscientious health professionals at drug treatment clinics about how they would cope when the one-year-only funding wore out and freshly recruited addicts in treatment could no longer be accommodated.

We heard tales of health care denied unless it required acute hospitalization, and we heard desperate pleas in New Jersey that something be done to insure that all hospitals participate equally in provision of underreimbursed AIDS care, rather than continue

the grossly disproportionate distribution resulting from the subtle "patient dumping" now practiced.

All this would have been troubling enough; but one could not escape the nagging awareness that if we are so far behind now, what will we do as the case numbers double within the next 2 years? And how can we be urging that people come forward for HIV testing using the lure of early interventive evaluation and treatment, when health systems are collapsing with one-tenth their number and when discrimination seems a far more likely result than compassionate care? The mere word disaster is not strong enough to describe what we have seen, for in a very real sense, the human has been leached from human services in a way that should shame us all.

I am a member, also, of the Global Commission on AIDS of the World Health Organization, and in November we met in central Africa, undertaking similar visits in an effort to appreciate the impact of the HIV epidemic there. I came back much shaken, for in Kinshasa I had seen hospitals where the beds were lined up 30 in a row with only enough space between them for family to stand and tend to their loved ones themselves since there were no nurses; and half those beds were filled with people with AIDS.

There was no pharmacy, no food service, no laundry; and the doctors had not been paid for several weeks. I thought, after that, that I had seen it all, but there were families there and they were doing their best, but after last week, I realized that even central Africa paled in comparison to some of what is happening in the shadow of the Statue of Liberty. We are seeing drugs and poverty and hopelessness and now HIV and AIDS threaten to complete the investiture of an underclass in our once-proudly classless land of opportunity.

By inattention we have let our cities slide into a silent social disaster. There are more homeless in New York in 1990 than there were at the depths of the Great Depression on the same population base, and now their ranks are being swollen further by AIDS. The despairing people in New York, in Jersey City and Los Angeles, in Newark and San Diego must find it harsh and bitter to hear about the wonderful biomedical research progress against HIV, about increasingly effective treatment for AIDS, and about the promise of early intervention when they cannot even get access to primary care. Even the emergency rooms on which they depend in times of crisis are closing their doors, as public hospitals teeter on the brink of collapse. It is, indeed, a disaster. There were no carefully engineered steel rods in the health care edifice that was so casually erected over the past several decades, and the crumbling has begun in earnest.

It is often said these days that AIDS is just one disease, that we have focused enough resources on it and should now move on to other diseases and issues. I could not disagree more strongly. In a very important sense, AIDS is a metaphor, the only really new things about the HIV epidemic are the virus itself and the pressure of burgeoning numbers of young adults needing sustained care. All the rest of the problems we face are old ones that we have ignored or patched or minimized beyond all common sense.

There is a ghastly public complacency in this country right now about the AIDS epidemic, stemming I fear from the sense that it is happening to others. Soon we will get over that, for we will all know someone caught in the sad web of blighted lives and premature death. We might have the help of that universal awareness even now, were not so many people grieving in secret for fear of discrimination or perceived disgrace.

We have had over 120,000 cumulative cases of AIDS in America, and over 70,000 have died. Those awful numbers will double and double again during this decade, even if we could stop further virus spread tomorrow.

We must recognize this for the disaster it is and respond humanely. And we must, at the same time that we take urgent action, proceed to make amends for the heartless omissions of past decades and plan carefully for the compassionate care of all our citizens. If we do so thoughtfully, our efforts will have benefits far beyond the range of the HIV epidemic.

I mentioned at the beginning that I had been to San Francisco in January, and it was a gleam of light in this dark time. There is no question there about whether AIDS is a disaster. And the task force report I helped to launch gave inspiring testimony to what a community can do when it pulls together to face the problems squarely, uniting business and health care and religion and minority and community activist groups with government in a common and coordinated response.

There is no doubt that the San Francisco plan will be demanding. In fact, I strongly suspect that emergency Federal relief through impact aid may constitute the marginal difference between success and failure. But the example of a united front against this awful disease reminds me again of the power of family, of just how powerful we can be in the face of disaster when we remember that we are all one human family. Thank you.

[The prepared statement of Dr. Osborn may be found at end of hearing.]

Mrs. BOXER. Thank you. Dr. Osborn, that was stunning testimony. Stunning.

I would like to take some excerpts and send them to our colleagues so that they can see what the chairman of our National Commission on AIDS is saying. Is that all right with you if we do that?

Dr. OSBORN. I would be very pleased with that. In addition, in the material I handed you, if it is easier—I was most flattered Congressman Louis Stokes took the time to introduce a talk I gave on World AIDS Day in the Congressional Record of January 31. I put the reference there. Clearly, our perceptions are expanding with each additional month. That gives some of the sense of outrage I feel on behalf of Americans in that talk, too.

Mrs. BOXER. Doctor, you were appointed by the President to this Commission?

Dr. OSBORN. No; the members of the Commission were appointed variously. Of 12 voting members, 5, including myself, were appointed by the Senate, 5 by the House, and 2 by the President. I was, as I mentioned, one of the Senate appointees and by the congressional

legislation that created us, the Commissioners then elected their own chairman. I was proud. They chose me to be the chairman.

Mrs. BOXER. They made a very wise decision. I cannot imagine a better spokesperson for this cause, not only for the Commission, not only for people with AIDS, but for people here in the Congress who have been trying so hard to carry this issue.

This is a country where, as you know, our people get excited for 30 seconds about an issue. This has been around a long time. The first time I got involved was 1983 with the supplemental appropriation of just $12 million. I wonder if you can tell this Task Force—and we will, of course, inform the full committee—what amount of dollars we ought to be looking at for AIDS this year, not in terms of treatment, but in terms of education and prevention and then looking at a separate program for impact aid and early intervention? Have you come up with some dollars amounts?

Dr. OSBORN. No; I am afraid my expertise falls well short of the kind of hard work you do in terms of genuine budget crunches.

On the other hand, I can give you a sense of how to proceed that stems from an activity I was part of. I was on the steering committee for the Institute of Medicine, National Academy of Sciences' study that brought out the volume called, Confronting AIDS in 1986 that you may have seen. There were people in that group who were much better at governmental and fiscal affairs than some of us. I am a pediatrician by background and an environmental scientist.

Nevertheless, in addition to doing that complex task, what we felt quite strongly was for every dollar spent on research, there should be a dollar devoted, an equal dollar devoted to health care and preventive education about the epidemic.

I think if you—the figures that I have been listening to with great interest today suggest that the recommendation originally made was about right for that; and what has been left is very largely the research side of that with a disinclination to get into health care and a very great reluctance to go full out and wholeheartedly in the area of prevention.

If we really want to stop this epidemic, I think we should be paying attention to what the military does when they really want somebody to volunteer for the Army. They don't say it once and they don't say it between 2 and 4 in the morning. They don't say it in euphemisms that cannot be understood. I think we nearly have to decide whether we don't care that much about our children's future other than in the Army and start imitating that approach to really educating our kids as to a new threat that is in the world out there.

So in terms of prevention, how much that would cost, every time I ask somebody, it depends upon how much time would be volunteered.

I am quite impressed to say, however, in Michigan when the Michigan Department of Public Health a couple of years ago came out with some unusually and straight spoken—tasteful but straight spoken public service announcement, the media of Michigan very quickly volunteered time for those to be aired in prime time.

In the southeastern Michigan area, in particular, there are ways of doing this that make it hard to estimate costs. I think if we had

a national will to go after prevention, it might be that it would not cost us an overwhelming amount as it looks it would.

In health care, I think the number of people have given you excellent testimony today. I think the only thing I would say about that is we must recognize we are on a rapidly moving track and the estimates for this year should be doubling for next year or for 18 months from now in terms of what we know about the things coming.

Mrs. BOXER. I would hope that you could take back the testimony of Mr. Waxman and Ms. Pelosi in specific and take a look at their recommendations. I think it would be very helpful for us as we move into the heart of this where we convince our colleagues of this, that we do put a number to your comments. That is really what we are about. Your comments have moved us. I think a number coming from the Commission would be very helpful to us.

Dr. OSBORN. I was most impressed with the analysis they presented and the charity of their numbers. I found it very helpful for myself. As I mentioned, I am not a budget person particularly. I thought that their analysis looked to me as if it was very much lined up with the kinds of things I do know about and will be eager to be as helpful as we can as the process moves forward.

Mrs. BOXER. Thank you very much.

Mr. Sweeney, I have just one question. You alluded to something that really hits me; that is, after we have invested billions of dollars in research and we know that for patients who are HIV positive, whose T-cells drop to a certain level, AZT is prescribed. Yet you are describing a situation where you believe there are many who are not being treated who should be. I would like to ask you if you feel as I do or maybe you feel even stronger than I do that it is completely immoral for this country to know that AZT works, to have spent the dollars to find out that it works, and then not to provide the ways and means for these people to get their treatment?

In other words, I think it is—I often said about the AIDS issue early on when, if you remember, the Reagan White House would not allow any mailings to be mailed, would not allow anything to get out, would not allow any TV commercials, anything mentioning AIDS.

I said I felt there were those at OMB who were really guilty of murder. When you know that a certain way to proceed will stop you from contracting a disease and don't act on it in good faith, you are not giving someone information. It is like seeing someone ready to step into the street and there is a car coming, the guy doesn't see it, and you don't say anything.

I feel the same way about the attitude about AZT by this Administration.

Mr. SWEENEY. I couldn't agree more. The crime I see is in New York, with these 117,000 people that are estimated, for instance, to be HIV positive and have a T-cell count below 500, the vast majority doesn't even know they are HIV positive and the vast majority doesn't even know about AZT.

What they will find out about is probably pentamadine and where they are going to find out about it is in an emergency room when somebody says you have pneumonia. They say what can I do

about it? Someone says do you know anything about pentamadine. That is when they will find out about it.

What I do not understand, and I second what Dr. Osborn said, that is we are the marketing geniuses of the world. There is one thing Americans do, that is sell. We can sell anything from tennis shoes to tennis tournaments. I cannot believe that we cannot put that same marketing genius to work here with a very simple prevention and education message. We have refused to do it. We have refused to do it because we have to talk about sexuality and drug use and we are uncomfortable with that. That simply cannot continue.

We now have very good news to tell people about something they can do for themselves. I think people will act in their best interests. I think the kind of money and time being spent arguing over coercive measures, testing, quarantining and other things are a waste of time. People want to hear the good news. They want to incorporate it in their lives.

We haven't given them the opportunity to hear that information. From what we have been saying today, we haven't given them a system to plug into once they want to act in their best interests and that of their loved ones.

I think you have absolutely characterized it correctly. It is outrageous.

Mrs. BOXER. It is outrageous. The reason I have these hearings every year, ever since I have been on the Budget Committee—this is my last year on the Committee, which distresses me greatly because of these issues of health and education I care about. That is the system. Someone else will come up here and do it.

But I think the reason these hearings are important, they are not only to find out the numbers we need to get into the budget, but to really expose issues in a leisurely way, because so much of the time we don't have a chance to look at where we are going from year to year.

You are so right. We have this incredible breakthrough with AZT and yet we do not have a system to deliver it and people will die because of it; and you are right. They will wake up in an emergency room. Without even getting into the compassion here, it is just stupid. It just doesn't make sense when we can keep people productive.

This Congress has to wake up. The Administration just wants to hear other things. They are not interested in this.

Mr. SWEENEY. I think part of the job in front of us, too, in education is redefining Americans' relationship with this epidemic. Many Americans looked at their own behavior and said I am not at risk, this is not me, it is the others. The others can stay over there. The truth is we have to redefine what being at risk for HIV is because their health care is at risk.

Your health care is at risk if you live in a city like New York, because if you get hit by a taxi cab and end up in an emergency room, your health care is at serious risk. You are going to join the other 28 people sitting on a cot figuring out how to get care.

People have to recognize they have perhaps a relationship they might not have assumed to HIV. Everybody's health care is at risk if the system faulters, particularly the public health system for the

poor. That is what we need to start saying to people, think about the next step. If, in fact, you don't think you are at risk directly, think about it as a taxpayer. Think about it as a citizen who needs the public health system or the health system at some level. That is a very big job in front of us.

Mrs. BOXER. Mr. Sweeney, thank you. Mr. Kildee.

Mr. KILDEE. Thank you for having this hearing.

Dr. Osborn, good to see you again.

Mr. Sweeney, we may be cousins. My grand grandmother was a Sweeney.

I think rightfully we will be judged very harshly if we don't make a major breakthrough in spending on AIDS this year. Rightfully judged very harshly.

I think it is a basic moral issue that this Budget Committee make the right priorities. This, in my mind, is an extremely high priority and we will be acting immorally unless we really make it so for the rest of Congress. This is where we make the first cut in this Committee right here. We have to really present, as Mrs. Boxer has been doing, Madam Chairman, for a number of years, to make this as a top priority in our national priorities.

I ask people sometimes how many people in your district died of communism last year. Not one in my district. Not one person in my district died of communism. Yet the President wants to spend over $300 billion for defense next year, which is in nominal dollars 6.6 billion more than we are spending this year.

Not one person in my district died of communism. Too many died of AIDS, too many died of drugs.

We really have to set our priorities. I think, for example, we should take money from SDI research—what they call research now—take money from SDI research and put it in research and treatment and information for AIDS. This is a real an enemy out there. We in the Congress have an obligation to look at what is a threat to this country and take our dollars and put the dollars where the threat really is.

But somehow this five-sided building across the river keeps getting all the dollars; $6.6 billion more. When you walk around the Capitol Building, ask every Member of Congress why do we need $6.6 billion more for defense when things are changing around the world and things are changing in the needs of health right now, AIDS being one of the greatest threats mankind has seen.

I just came from a meeting with the NAACP back here to hear your testimony. Thank you for it. I think we have an opportunity this year.

Mrs. Boxer, this is your last shot, your last hurrah as a member of this Committee. You did great in the Budget Committee last year. There was some slippage in the Appropriations Committee. We really have to push a little harder this year and say this is a top priority of the country. People, like yourself, have made us more sensitive to that. A thank you for that. March around the Hill and let them know, too. Thank you very much.

Mrs. BOXER. Mr. Kildee, thank you so much. I know when I do leave the Committee, you are right there stepping right in. I think your comment about the priorities is right on target. Let's face it.

That is where it will come from. We better face it. We better get people involved in the debate.

Thank you both very much. You have been just very fine witnesses.

We will call the panel on early intervention, Dr. Mark Smith, Chuck Meyer, Dr. Mitchell Gail, and Dr. Peter Arno, all very prestigious. We welcome you. Welcome, gentlemen. We are going to start with Dr. Mark Smith, associate director of AIDS Services, Johns Hopkins University Hospital.

Gentlemen, if you want to put your statements in the record and we can hear from you in summary form, that would be fine.

STATEMENT OF MARK SMITH, M.D., ASSOCIATE DIRECTOR OF AIDS SERVICES, JOHNS HOPKINS UNIVERSITY HOSPITAL

Dr. SMITH. Thank you, Madam Chairperson. I welcome the opportunity to talk with you today. You have heard an impressive array of people so far and will hear from others whose work I know and respect.

I would like to briefly raise and perhaps answer three questions and then give you one note of caution. The three questions are: (1) Why is early intervention important? (2) What about other people who are sick, what about their needs, what is often called in these discussions the equity argument or the parity argument? (3) Is the need here really for more money?

The one caution I would offer is the caution not to forget the needs of prevention.

Why is early intervention important? There are two ways to address that. From my perspective, we have a definition, conception of what HIV disease is from what we had when the word AIDS was first coined and when the CDC definition of AIDS was first developed and even modified.

AIDS is a surveillance definition of the last stage of HIV disease. Very clearly, those of us who take care of HIV-infected persons are now dealing with this disease as a chronic disease, a disease that is a spectrum from the asymptomatic to the terminally ill.

So increasingly, when entitlement programs like Medicaid base their capacity to pay for people's treatments on whether someone is at the last stage of an illness which we now recognize as encompassing a whole spectrum, it wreaks havoc with what makes medical sense in terms of treating people.

As you heard from Mr. Sweeney, and I can testify that this is true, we now know how to deliver more care biomedically than we know how to deliver socially and economically.

So during the month of January, when I was the attending physician on the Oshler-8 inpatient service, the AIDS unit at Johns Hopkins Hospital, we saw patients who have known for a year and a half or more that they were HIV positive, let alone those who didn't know. We saw people who knew they were HIV positive who were, to the best of our ability to tell, never counseled about the importance of their T–4 counts; never offered zidovudine or AZT; never offered prophylaxis, preventive therapy against pneumocystis.

We saw people in the hospital. By the time they get into the hospital, Medicaid will pay for them. We saw people in the hospital who were staying for 2 weeks, 3 weeks and sometimes longer at tremendous financial cost and at tremendous costs to them in ways other than financial with diseases that were if not preventable, certainly delayable; but diseases whose prevention or whose treatment in the early stage cannot currently be paid for by our existing insurance mechanism.

The first answer to why early intervention is important is because we have changed our conception of how to take care of this disease.

The second reason has to do with the fact that people with HIV disease have shifted their attention, and their physicians and other care givers have rightfully shifted our attention, from not how to help people die with this disease, but how to help people live with it. It is, as you have heard and as you know, a disease for which we still have no cure.

In answer to the question, If you give people preventive therapy for pneumocystis or AZT, aren't you simply delaying the point at which they get sick? my answer is yes. Hopefully, delaying it to the point where we have new therapies to offer them. In fact, while that may be a pipedream for some diseases, for HIV disease it is quite real, because the therapeutic advances take place quite rapidly. We are very hopeful that people whom we are able to keep alive for another year or two will be able to benefit from therapies which we have not yet established to be effective.

So, unlike some other disease, where a question might be raised about the overall value of delaying death, in this disease it is clear that buying time is an important thing to do, because we are buying time to hopefully develop more therapies that can be offered.

The second question, What about other people who are sick? I agonize over this question, as I am sure you do. I don't think any of us are here because we want only people with HIV disease to get the best care. I certainly, as a general internist, see lots of people with diseases that could be prevented or ameliorated who don't get adequate care because of their insurance status.

The outrage of our not being able to provide AZT once we have demonstrated it is effective is matched in lots of other diseases. We don't provide Pap smears. We now they are effective. We don't provide lots of preventive therapies, big-ticket and often little-ticket items whose effectiveness has been demonstrated.

Again, I have two answers. The first is that this is the only disease I know of where one is subject to being kicked out of one's house for having it. It is the only disease I know of—except, perhaps, the disease of poverty-where you are likely to be sent from one hospital to another in an effort to put your care off to someone else.

So there is no question that there are specific obstacles to care that people with HIV disease face.

My second answer, however, is I agree. If it were politically possible to extend Medicaid coverage to asymptomatic people who need treatment for their disease, whatever the disease, I would be all for it.

So, to the extent that our health care system and its coverage have been improved, for the most part by incremental steps, I support an incremental step which I think is not contrary to the spirit, but goes along with the spirit of trying to improve our ability to provide access to high quality care for everyone.

I don't think we should pit providing quality care for people with HIV disease against providing quality care for people with other diseases. I, at least, and I think other members of the panel would be for that for everyone.

The third question is, Isn't it a problem of more than money? Or, as it is sometimes put, Can you solve this problem by throwing money at it? The short answer is yes. Or really, the real answer is that you certainly don't solve it by not throwing money at it.

Closing the gaps that exist in providing adequate facilities and providers for people with HIV disease is a complex problem. There are problems of ignorance; that is, there is a need for more medical information, education for physicians and others. There are problems of prejudice against gay people and against drug users. There are problems of fear of infection because occupational transmission of HIV is small but a very real possibility.

There are fears that other paying patients, be they in nursing homes, or hospitals, or physician's offices, will seek care elsewhere if they know that they are sitting alongside of or in a room next to one with AIDS.

All of these are real factors. But I, too, grew up in New York. When I was growing up, there was an ad that said money talks nobody walks. The fact of the matter is that if you ask a physician to run a small but real chance of being infected, to struggle with ones own internal prejudice and biases against people with alternative lifestyles, to run the risk of dissuading some other patients from coming to you all that is enough; but to ask someone to do that and go broke in the process is something which has produced the result we now have—which is crying gaps in services.

So while I think the provision of adequate intervention facilities, be it for administration of prophylaxis against pneumocystis, administration of zidovudine, has to do with new facilities in some instances, professional education and antidiscrimination laws, the fact of the matter is that health care is a business that runs on reimbursement, runs on payment.

To take up all those other issues without first assuring that people will be adequately reimbursed for the care we expect them to provide is, I think, a futile endeavor.

The last point I want to make is to caution us against the understandable tendency to forget about prevention because of our excitement about the good news in therapy.

I am a doctor. I take care of people. I am on the side of this equation that deals more with the care part than the prevention part. Yet, I think I speak for all of us who are clinicians who take care of people with HIV disease, that we do not want our newly discovered and newly emerging therapies to be the thing that takes money away from the much needed preventive task which is far from over.

There is, I think, a tendency on the part of legislators, local, State and even Federal, to regard AIDS as one pot. So when we are

talking about spending AIDS money, if the doctors and the economists come to us and say it is going to mean 5 more million to take care of people, there is an understandable tendency to say, well, let's take it out of the rest of the AIDS money, cut down on research, prevention. That is an understandable tendency.

I think it is dead wrong. The fact of the matter is that increasingly there are some populations whose educational tasks will be long fought and hard. Those populations have not yet been reached by the message that some have been. We have a lot of work yet to do.

Those of us who take care of people with HIV disease certainly want resources to be devoted to that care. We also want resources to be devoted to the task of making sure that we will not have so many patients 2 years and 3 years and 4 years in the future.

Thank you very much.

Mrs. BOXER. Thank you very much for that testimony.

Mr. Meyer, National Association of People With AIDS, Chair of the Committee on Medical Affairs. Welcome. Again, you could read your testimony or you can summarize it, if you will.

STATEMENT OF CHUCK MEYER, NATIONAL ASSOCIATION OF PEOPLE WITH AIDS, CHAIR, COMMITTEE ON MEDICAL AFFAIRS

Mr. MEYER. I do have testimony for the record. I will try to summarize it. I know you are short on time.

Madam Chairman, members of the Task Force, ladies and gentlemen, on behalf of the National Association of People with AIDS, an organization of, by, and for people living with AIDS and HIV, I would like to thank you for the opportunity to address the issue of early intervention, which we feel is an issue whose time has come, that the treatment of HIV today is a reality, that the issue around early intervention in the human immunodeficiency virus has been proven by science, by the research done, funded by Congress, by the DCA's approval of AZT in HIV treatment for people with helper cells below 500.

The evidence is all there that early intervention works. I am the real evidence that early intervention works. I have lived with HIV infection for well over 7 years but began treatment in January 1987 with a research protocol therapy known as DIC.

I began therapy in January after a long battle of trying to get identified as to what was going on with my health. Up until just the last year or so, many people with HIV fought a long, nasty battle with the health care system to get their diagnosis recognized, to be dealt with as a disease that was treatable rather than a fatal condition that the only help there was for it was the help in the writing of a will.

Many of the AIDS organizations that helped us up to a few years ago, that was all that they had to offer. Today we know that that is not the case; but even though we have the therapies to offer people with HIV, even people like me who have returned to be productive once they have been diagnosed with AIDS-related conditions, even though we have these therapies, there are many, many people out there with HIV, many that I have as personal friends from over the years in the gay community and many that I worked with

through the National Institute of Drug Abuse as an AIDS education specialist in the IV drug community for over a year, my biggest concern is that I would say the vast majority of HIV-infected people in this country are not only not aware of early intervention and not aware of how to apply early intervention to their lives so they may live with this virus, but they don't believe it is true. They don't even believe that AZT necessarily works.

I was at an advocacy meeting in Phoenix, AZ—Arizona is where I am from, by the way—about 2 weeks ago. I was trying to get some backup for some legislative work we were doing in Phoenix, trying to get the Governors' task force report to influence legislation. There are a lot of issues on early intervention and treatment. Many of the AIDS advocates and activists in that room who worked with people with AIDS in Arizona now for 5 or 6 years told me to my face—one quote verbatim was, "Early intervention is media hype and government lies." And that it is not a reality to the people who are infected with this disease.

Our friends are still dying. People are not getting treatment; and all it is is a hype to take the pressure off the government, and we still could not have an answer for AIDS.

Now personally I don't believe this, but there are many, many of my friends that do believe this. Personally I believe that we have begun but only begun to find the therapies that help people live with this virus. But they are no good if people haven't got access to them, if people in the IV drug community believe that any kind of treatment for HIV is strictly a luxury of the affluent white gay male. That brings us nothing if that is what the majority of people believe.

We have in Arizona through the People with AIDS Coalition of Tucson and through various AIDS organizations tried to bring about voluntary encouraged testing for HIV. We have finally, a year ago, gotten the State of Arizona to approve anonymous testing so people could voluntarily find out about their status and begin to monitor their health, begin to look into treatment therapies so they can live with this virus.

We still do not have the funding or the assistance, either through the State or through the Federal Government, to educate people on the realities of early intervention, how to find therapy, how to get into treatment.

We used to say that we had all the help we needed writing wills, but nobody could help us get into a research protocol.

So my biggest concern at this point is that especially within the IV drug community of which I now have many friends from working with NIAADA. In fact, one called me the other day here in D.C. very distressed because her helper count dropped below 400 and her doctor told her 2 months ago she could get on AZT.

Because she is a former IV drug user, they told her she probably couldn't afford AZT anyway and after all with your life style, how are you going to stick to AZT therapy when you are on methadone and have a child to take care of.

The woman is totally discouraged and suicidal. She called me from Tuscon distressed that her doctor was on vacation, that he had told her over 2 weeks ago her helper count dropped—when it did drop, that she could go on AZT, but she still is not on AZT. She

developed a form of uterine cancer and has infections in her eyes that they have yet to do any treatment other than an eye wash.

This woman is trying to raise a 2- year-old daughter that she give birth to with HIV infection. When the doctors told her that immediately she should have an abortion, her husband said if you don't have that baby, I will kill you. She went ahead with the birth of the baby. Thank God, the child at 22 months is still healthy.

This mother is trying to raise the child with the fear in the back of her mind that at any time she may develop symptoms of HIV, trying to deal with her own health and getting little or no assistance on treatment therapies and the ins and outs of dealing with the health care system.

So, I would hope that the realization that early intervention is going to impact our health care system in a positive way as far as the cost effectiveness of early interventions versus acute care in the very sick, that we can help the health care system by getting early treatment for people, keeping these people, myself included, productive; we even pay taxes when we are productive.

Three years after an AIDS-related diagnosis, we are able to still pay our taxes. I think that is a good sign.

If we can help these people not only access the medical treatment but learn how to work the system and learn how to live with HIV, we are going to have many, many citizens with HIV productive for a very long time.

I would like to thank you for your time and your concern over this issue.

Mrs. BOXER. Well, I thank you very much. You certainly are a living example of what we are talking about.

Dr. Smith, I meant to tell you I don't even know—I think you know this, Nancy Pelosi and I nominated you for that AIDS Commission. After what I heard today, I really regret you are not on it.

Dr. SMITH. Thank you.

Mrs. BOXER. You are really terrific.

Dr. Mitchell Gail, National Cancer Institute?

STATEMENT OF MITCHELL GAIL, M.D., NATIONAL CANCER INSTITUTE

Dr. GAIL. Thank you, Madam Chairman, and members of the Task Force.

I am pleased to be here today to present work done in collaboration with Drs. Philip S. Rosenberg and James J. Goedert of the National Cancer Institute. We wish to acknowledge the help and constructive suggestions of workers at the National Institute for Allergy and Infectious Diseases, the Centers for Disease Control, Johns Hopkins University, and the University of California at Berkeley. As a researcher in medical statistics at the National Cancer Institute, I am here to discuss the scientific aspects of this work.

Since mid-1987, counts of national AIDS incidence have fallen below previous projections in certain groups, such as homosexual and bisexual men, but not in other groups, such as intravenous drug users.

You can see in figure 1 there is an abrupt improvement in incidence figures for homosexual and bisexual men beginning in the

middle of 1987. In figure 2 for intravenous drug users, you see no such improvement.

Although factors such as changes in reporting patterns and changes in behavior that reduced the earlier rate of transmission may have contributed to these favorable incidence trends in homosexual and bisexual men, we believe that the decreases seen have resulted mainly from the increasing use of zidovudine (AZT) since March 1987 and possibly from other treatments that can retard the onset of AIDS-defining pneumonia.

Although these favorable incidence trends mark an important advance in the treatment of persons who are infected with the human immunodeficiency virus and who have severe immunodeficiency, these favorable trends in incidence are not grounds for complacency.

We believe that the abrupt improvements in incidence beginning in 1987 primarily reflect the impact of new treatments and do not imply that fewer persons are infected with HIV. Indeed, our statistical models and completely independent survey data from the Centers for Disease Control indicate that about 1 million persons are infected with HIV in the United States. Moreover, new infections continue to occur at an estimated rate of over 100 per day.

Several implications follow from these facts:

One, many of these 1 million infected individuals will eventually progress to AIDS, despite treatment, unless a cure is found. Thus, current incidence trends should not be misconstrued as suggesting that the AIDS epidemic is on the decline. For the country as a whole, AIDS incidence continues its upward course.

Two, with so many infected, the potential for further spread of HIV infection remains great. Prevention efforts should remain a primary goal as many people have stressed today.

Three, populations without adequate access to zidovudine and other treatments should be identified, and providing access to treatment, especially for those with severe immunodeficiency, should remain a priority.

Four, further research is needed to validate our findings and to quantitate the extent to which other factors may be contributing to current trends in AIDS incidence. Possible factors include changes in AIDS reporting patterns as well as behavioral changes that have reduced the transmission rate of HIV infection in some exposure groups.

Five, research is needed to strengthen our tools for controlling the impact of HIV infection, including strategies to prevent the further spread of infection, especially among intravenous drug users, to develop improved treatments, and to provide medical access to treatments of proven efficacy.

Thank you for this opportunity to speak and to clarify questions you may have about the data presented here.

[The prepared statement of Dr. Gail may be found at the end of hearing.]

Mrs. BOXER. Thank you very much. I think this is very important information and really contradicts a lot of what we are hearing in the news that we are out of danger, we have not got a problem, et cetera.

Dr. GAIL. Right. I think, as your comments suggest, if you have treatment in mind, what you can understand is that incidence rates can be stablizing in certain subgroups, but many, many people are still infected and infections are still continuing because the favorable changes in incidence are due to treatment and not to reduced numbers infected.

Mrs. BOXER. When you talk about 100 cases a day, I think that is extremely important that we get that information out.

Dr. GAIL. There are recent studies that suggest that that is a minimum figure.

Mrs. BOXER. Dr. Peter Arno, Department of Social Medicine, Montefiore Medical Center.

STATEMENT OF PETER S. ARNO, Ph.D., DEPARTMENT OF EPIDEMIOLOGY AND SOCIAL MEDICINE, MONTEFIORE MEDICAL CENTER/ALBERT EINSTEIN COLLEGE OF MEDICINE

Mr. ARNO. Madam Chairman, thank you for the opportunity to testify before this important Task Force. I am a health economist at Montefiore Medical Center and the Albert Einstein College of Medicine. I will make a brief statement and submit a longer one for the record.

During the past year, major advances in the treatment of HIV disease have been made. In August 1989, the largest clinical trial ever conducted among persons with HIV disease was halted when low dosage AZT was found effective in slowing progression from HIV infection to AIDS.

Based on the findings of this study, the Food and Drug Administration just a few days ago, March 2, 1990, approved a new labeling change for the use of AZT among HIV-infected individuals prior to an AIDS diagnosis.

The National Institutes of Health held a consensus conference this past weekend on AZT therapy for early infection and endorsed the FDA labeling change. The NIH panel "strongly recommended that AZT therapy be initiated for asymptomatic HIV positive individuals with CD4 lymphocyte counts below 500."

Progress has also been achieved in preventing and treating opportunistic infections, particularly pneumocystis carinii pneumonia.

Thus, specific antiviral therapy and chemo prophylaxis for some opportunistic infections represent major clinical advances in the management of HIV infection. These advances may, indeed, account for some of the recent developments we have seen in the survival rates among persons with HIV disease as well as the lower than expected incident cases of AIDS, as we have just heard from Dr. Gail.

Understanding the meaning of an effective early intervention strategy requires us to shift our thinking of this epidemic by an order of magnitude.

From the point of view of the health care system, we can no longer think of the 50,000 persons living with AIDS in this country requiring a wide range of medical and social services. We must now consider the other 800,000 to 1 million person who are HIV infect-

ed who require a new set of health and social services that are not even fully conceptualized let alone available.

The organizational and financial demands of an equitably distributed early intervention program are considerable. This includes the provision and coordination of ambulatory care services for large numbers of new patients. The ability of our health care system to fulfill this task by providing adequate HIV testing, counseling, laboratory monitoring, medications and overall primary health care is currently inadequate.

These difficulties are compounded because a growing number of persons with HIV infection are intravenous drug users, there sexual partners and families who live in neighborhoods that are the most medically underserved and understaffed.

To accomplish these goals requires nothing short of revamping the ambulatory care network in our inner cities, such as it is.

To relieve the crisis in the hospital sector and to provide care to those that need it will require major new resources and new funding streams for primary care. Expanding categorical eligibility under the Medicaid program as suggested by Congressman Waxman in H.R. 4080 will go a long way to improving access to primary care and to life-prolonging medications and is certainly a step in the right direction.

However, we should be mindful of the system we are creating access to. Why is it that for a routine physician visit for a new patient in New York City, Medicare pays $81, Blue Cross pays $84, and Medicaid pays $12, or for a bronchoscopy, Medicare pays $750, Blue Cross pays $775, and Medicaid pays $60?

Correcting these differentials is long overdue and absolutely necessary if we want to provide a semblance of equity in access to care for all our citizens. To illustrate the problem another way, I would like to read to you a short anecdote related to the New York State Assembly Committee on Health at a recent hearing on primary care and HIV.

An attorney with private health insurance described how his primary care physicians played an essential role in his treatment plan. He then described this recent incident of someone less fortunate.

"The social worker of a Latina woman in the Bronx who recently tested HIV positive called to tell me about her client. The woman tested positive and was fortunate enough that she knew to follow up with a T-cell test. A Medicaid recipient, she went to the clinic at the public hospital in her neighborhood. A blood test was done and every 2 weeks she returned to the hospital and was told her results had not been received. She speaks little English. Finally, after waiting 10 weeks, she returned to the hospital with a social worker who speaks Spanish. They waited for 3 hours only to have the doctor tell her again her test results were not available and that she should return in 2 weeks. The doctor then said to her since she was HIV positive, she should start taking 1,500 milligrams of AZT a day, wrote a prescription, and left."

Is this the type of bifurcated early intervention strategy we are building, one for the well-educated and well-insured and another for the poor who must rely upon government-sponsored programs?

I do not believe that HIV disease is a series of local problems which can be solved by new policies at the city or state levels alone but what has been desperately lacking during the past 9 years of this epidemic is national leadership and a Federal AIDS program. The Kennedy-Hatch bill—the Comprehensive AIDS Resource Emergency Act of 1990—introduced this morning to provide emergency relief to the Nation's hardest hit regions, provides a ray of hope to our beleaguered citizens, their health care systems actions and the hundreds of thousands of HIV-infected persons who are our neighbors, families, friends, and loved ones.

In addition to an infusion of Federal resources, the enactment and endorsement of strong antidiscrimination statutes would ease the transition to wider acceptance of voluntary testing, monitoring and treatment programs.

What is all this going to cost and how can it be financed? Great uncertainty surrounds most of the parameters one needs to estimate to determine the costs for an early intervention program that is national in scope.

However, we must act in the face of uncertainty. Taking into account the latest FDA and NIH recommendations, I have refined our model to estimate the demand and costs for the first year of a national early intervention program if it were in fact begun in earnest.

There are three major components to such a program. The first is testing and counseling, $35 million; the second would be monitoring seropositive populations, $211 million; and the third would be treatment, $951 million.

All told, this program would cost approximately $1.2 billion during the first year which represents less than one-half of 1 percent of total national health care spending. Moreover, these costs would not be borne solely by the Federal Government. Along with the central role of the Federal Government, costs would be distributed to states and localities through Medicaid and other public health programs and to the private sector through the health insurance industry.

The veil of medical uncertainty regarding early intervention has been lifted by the recent FDA and NIH recommendations. The time for equivocation is over. We must act now. And we need your help and the help of this committee and the help of Congress to do so. Thank you.

[The prepared statement of Dr. Arno may be found at end of hearing.]

Mrs. Boxer. Thank you very much. I particularly appreciate your specific numbers. They pretty well describe with what we have been hearing. Again, I think the issue will be to this Administration that they have to realize when they cut back on the health professionals unbiases, if you will, reasoning as to why we need certain funds and then they just—OMB comes in and says, no, we can't do it, and then they brag about the AIDS budget. By the way, when this budget was submitted, they bragged about the AIDS budget. We really have a fight on our hands.

I don't have any particular questions to you. I just want to pick up on Dr. Smith's discussion about pap smears. It is an interesting analogy. It is a little different than AZT. We are talking about get-

ting AZT to people who absolutely have to have it because they are HIV positive. Women need to have a pap smear. It is a lot cheaper to get a pap smear than to go on AZT for the rest of your life.

I think what is interesting about the pap smear example is we did act to get the pap smear into the doctor's office so since we did that, and we made it available, the death rate from cervical cancer has dropped dramatically. If we would get as many women to do mammograms as have pap smears, we would see a reversal in the breast cancer death rate as well.

I think what I am saying to you is there is an analogy here. We have made some progress on the cervical cancer front. We would make more if we could do more with the mammography and pap smears.

I think your point that we shouldn't pit one disease against another is absolutely critical. To me that is really a horrible thing to do. It is a very cynical thing to do. It is what we have seen sometimes coming out of that Administration in very subtle ways. So we are talking about health care here. We are talking about prevention.

I also appreciated your comments about not getting lax on prevention. That is really why we decided to have a panel on prevention and research. I remember in my office the good people who talked to me who said, Barbara, you can't let up. They have the same sense you have, that we can never discuss AIDS without discussing prevention because obviously that is the name of the game.

If we can truly prevent, we wouldn't have to be here with these discouraging statistics.

Well, I just want to thank all of you very, very much. You have been terrific. Your testimony will be sent out to Members of this Committee. We will use your testimony as we make this fight. So feel very proud about the fact you were here. I thank you very much.

Our last panel is on prevention and research, Dr. Kathleen Sheridan, from Northwestern University; Dr. Debra Fraser-Howze, executive director, Black Leadership Coalition on AIDS; Marie St. Cyr-Delpe, executive director, Women and AIDS Resource Network; and Jean McGuire, National Organizations Responding to AIDS.

Welcome all of you. We would ask you to either read your testimony into the record or submit it and summarize as you wish.

STATEMENT OF KATHLEEN SHERIDAN, Ph.D., NORTHWESTERN UNIVERSITY, ON BEHALF OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION (APA) AND THE PREVENTION TASK FORCE OF THE NATIONAL ORGANIZATIONS RESPONDING TO AIDS

Ms. SHERIDAN. Thank you, Mrs. Chairman. Thank you for this opportunity to present testimony on AIDS prevention funding.

I am a behavioral scientist from Northwestern University. I am also codirector of our outpatient services for people who are HIV infected. We at Northwestern have 850 patient visits a month.

Although I am here on behalf of the American Psychological Association and the National Organizations Responding to AIDS, I

am a voice from the Midwest and a voice that I think needs to be heard very loudly now.

We are not Los Angeles; we are not San Francisco; we are not Miami, New York, New Jersey, but we are Chicago and the Midwest today, and what we are in Chicago will be Columbus, Milwaukee, Minneapolis, Des Moines, St. Louis tommorrow and other smaller communities like downstate Illinois in 3 or 4 years.

The Midwest is experiencing extremely high rates of new infections with HIV. The National Organizations Responding to AIDS $789 million budget request for targeted prevention services is money our Government and we as citizens cannot afford not to spend. Without it, we are in real danger of losing our youth to drugs and this disease; our teenagers to prositution, crime, street life and this disease; and our infants to this disease.

Let me highlight three points and then allow me to tell some of the story in Illinois.

First, we do have new treatments for HIV disease and for AIDS. Aerosolized pentamidine, lower dose AZT, early intervention, I know that, I am a director of an ambulatory clinic, but we cannot persuade ourselves that we no longer need prevention as a chief priority. It simply isn't true.

Second, we are far from winning the prevention war, and we cannot be persuaded that we are any closer to winning than we actually are. Surely information gained by gay and bisexual men has changed their behaviors which led to the risk for the HIV infection, but many of these men have done so in 1984, 1985, 1986. What of the younger men who are now entering young adulthood, teenagers at that time? They haven't heard any prevention messages.

The second part of that is what about maintaining behavioral changes over time? Maintaining that behavior is not simple, and it is not easy. Prevention is not a one-time thing. It must be repeated. It must be encouraged, and there must be a continual monitoring if those changes are to be maintained. Any of us who has dieted, exercised, stopped smoking, drinking, or biting our nails knows exactly what I mean.

Third, let us dismiss the idea that this is a tug of war between prevention dollars and treatment dollars. We need both, and we need them desperately.

Illinois has about 3,600 reported AIDS cases, 2,600 of those are in Chicago, 3,200 of those are in metropolitan Chicago. Our Sunday Chicago Tribune just this past week reported a 50 percent increase in AIDS cases in our Chicago suburbs. Last year, however, we spent $1.8 million on targeted AIDS prevention programs, using both State and Federal funds.

That amounts to about 16 cents per each of our 11.5 million citizens. But we have done a lot in the area, and we need to do so much more. Thus, I would like to use the AIDS strategic plan for the city of Chicago presented by the AIDS Advisory Council, of which I am a member, to Mayor Daley in October 1989. I would like to submit this document for the record, if I might.

Mrs. BOXER. Absolutely. It will be submitted.

[At the time of printing, the document had not been submitted.]

Ms. SHERIDAN. Thank you very much. We have several prevention programs in Chicago, and I would like to highlight just a few.

We are one of NIDA's 63 AIDS outreach projects for IV drug abusers. Projects like ours have increased the proportion of users who clean their equipment from 6 percent in 1985 to over 70 percent in 1988.

I think you know that comes from John Waters' work in San Francisco. More people are moving into drug treatment programs as a result of those outreach projects for IV drug abuse, and they are cost-efficient. They cost $100 to $200 per user per year.

Yet, these funds are scheduled to be phased out by ADAMHA. We have 63,000 or more users on the streets in Chicago, apparently uninfected. But with great alarm, I have to report to you that 10 percent of the IV drug users in Chicago are becoming infected each year.

If we barely reached half of them, we would need $3.5 million. In Chicago we have 25,000 female prostitutes. Some 60 to 80 percent of them are prostitutes in order to pay for their drug and alcohol habits, and we have one AIDS outreach program for them, although it is a giant in terms of what it has done. This is Genesis House. These prostitutes are not the glamorized people we see on TV miniseries. These are 14-year-old girls, washed out, scraggly hair, vacant stares who have nowhere else to go, but they need to do something to try to support their drug habits. They are on the streets and they are homeless.

Genesis House goes out on the street with their street ministry. They go to the lockups in the jails. They go to courtrooms, two courtrooms in the city that handle all prostitute arraignments. They have reached 5,000 of these women with messages about having their customers use condoms, a chance to join support groups, a place where they can come to get off the streets, and in order to reach 20,000 more we need $650,000 a year.

The Neon Street Center is a place for homeless, throwaway youngsters and teens. It is a drop-in center and it also does outreach on the streets with street ministers. For all of Chicago, we have 10,000 homeless youth. We need $1.8 million to support these programs. Downstate Illinois AIDS cases increased by 92 percent between 1988 and 1989. That is a rate of increase like that of Chicago 3 to 4 years ago.

East St. Louis, which is a city desperately trying to survive, is very much what I think the South Bronx must be like in New York. At the same time the parents of youngsters in East St. Louis are very wary about prevention and about messages about AIDS. We need to try to help those parents understand that we have to give out this information or their youngsters are going to be in a great deal of trouble.

Even in rural communities, such as Mt. Carmel in Illinois, which reached national attention last summer, a community of 5,000, they found an outbreak of non-A, non-B type hepatitis, which is only associated with IV drug use. That was an alarming way for that community to learn that they had a real problem on their hands.

In summary, when we look at all this, our request, NORA's request is modest, $789 million for targeted AIDS prevention programs, and their evaluation by the Centers for Disease Control and

ADAMHA is modest. What we need to do is to expand community-based prevention programs to drug users.

We need to continue prevention programs for gay and bisexual communities. We need to incorporate culturally sensitive programming for our ethnic and racial minority communities. We need to restore funding cuts in NIDA drug abuse outreach demonstration programs.

Drug-related infections is the fastest growing route of HIV infection. For ADAMHA to cut back on this funding is nearly unconscionable, and it is frankly incredible. We must maintain the number of new and competing AIDS prevention research grants at the fiscal year 1990 level and properly fund randomized trials of prevention interventions as recommended by the National Academy of Sciences, and finally we must fund mental health services research demonstration programs as authorized by Congress in order to effectively sustain behavior change.

I thank you very much for the opportunity to testify today.

[The prepared statement of Ms. Sheridan may be found at end of hearing.]

Mrs. BOXER. Thank you very much for bringing these issues home to us.

Our next speaker, Debra Fraser-Howze, executive director of the Black Leadership Commission on AIDS, we welcome you. Please proceed.

STATEMENT OF DEBRA FRASER-HOWZE, EXECUTIVE DIRECTOR, BLACK LEADERSHIP COMMISSION ON AIDS, NEW YORK

Ms. FRASER-HOWZE. Thank you very much. Good afternoon, Madam Chairman.

I, first of all, have to correct this. This is the second time this week that I have been called doctor. I thank the folks for the prestgious degree.

Mrs. BOXER. We will make you an honorary doctor.

Ms. FRASER-HOWZE. I am very grateful for your invitation to be here today to give testimony. I am here to speak for the people who don't have a real strong voice in this epidemic, people who have been devastated by excessive death rates long before AIDS, and the blacks and Hispanics in New York City who now make up 61 percent of this disease.

African American and Latino children, as the Mayor told you this morning, make up about 91 percent of all infected children with AIDS in New York. This disease is a very different disease in communities of color, and it is a disease that is killing our children.

I want to tell you a little bit about the Black Leadership Commission on AIDS. The Commission was formed in 1987 with 69 members of the city's black leadership, consisting of clergy, politicians, social policy experts, agency executives, business leaders, and medical professionals. They came together to try to develop strategies to reduce the spread of AIDS among the African American community. Again, in communities of color the disease is very different, and the disease is killing our children, and that is a major concern there. The Commission's goal is to improve the health care and services to African Americans infected with AIDS and their

families, through providing technical assistance in management and funding to community-based organizations formulating policy. Advocacy, we are probably one of the strongest advocacy groups among people of color in the city of New York, and programs that address mass education and community development and a lot that focuses on the development of the black church around this epidemic.

So we have studied our community very, very hard, and we are going everywhere we know that there is a single possible hope of a resource, and we are trying to use them the best that we can. We do not have any money from the Federal Government to do this. We are doing this all on our own. I have two real concerns, though, as I sat here and heard some things said today, even from some of the most respected experts that I know in this business.

One, as we began to talk about AZT, of course everybody is aware that AZT is not a cure, but Marie and Chuck and I have been with ACTG—the AIDS Clinical Trial Groups—all the scientists who have come together, they are right here in Bethesda for the last couple days. I have been working on a draft about AZT. There is one thing that strikes me about the drug that I don't know if everybody is completely aware of, the testing that has gone on around AZT and the clinical trials don't include people who look like me for the most part.

I mean, when we asked some very specific questions as to what effect will this drug have, if there is any toxicity, on women or women and men of color they couldn't answer that because there have not been enough men and women of color in these clinical trials to even study how this drug is going to act on us.

That has got to do with education. We do not know that the trials are even available or that you can even access the drug for the most part in the city of New York, and that, I think, is discrimination beyond any level of any discrimination that I have ever seen before.

The other thing is that I hear people identifying AIDS and HIV infected communities of color solely with intravenous drug abuse, and as the Commission studies the African American community and the number of women and children that are being affected by this disease, we know and we stress more and more not to just link HIV infection in communities of color and drug use because it is not a message that all of the women who are going to be potentially infected can hear.

Women feel in New York City right now, in the black community, if they are not presently sleeping with an intravenous drug abuser who is nodding on the corner of 125th Street, there is no way for them to be infected. I have a 21-year-old graduate of Vassar, a 20-year-old graduate of Columbia, and the 11-year-old and a 2-year-old, and I can tell you that from where I sit right now, I have several friends that do very well in business and education and in social welfare in the city of New York, and not one of them, not one of them can say that they have not exhibited something within the past ten years that puts them at risk of this disease.

And if we keep saying when we talk about communities of color, communities of color sometimes we don't even use that word, we just say IVDU's, as if this is the only part of our community that

we have to be concerned with. If we promote that language, the experts of us that do that, then we are really doing a grave injustice on our communities, and I felt really compelled as I sat here to say that.

I do not belong to the intravenous drug abuse community, but I am just as much at risk as the young woman that Chuck spoke about earlier who has the 2-year-old child and is worried about her AZT. Sixty-one percent of the people with AIDS in New York City are black and Hispanic, and clearly that chart is outrageous.

If you took San Francisco and Los Angeles and linked them together, we would still have more AIDS cases than anybody else. You know, a recent article in a prestigious medical journal examining excessive deaths in communities of color stated that a black man in Harlem has less of a chance of living to the age of 65 than a man in Bangladesh. Now, this study was based on data that is 10 years old, and it preceded crack and AIDS in communities of color, and you have to ask yourself why should a black man in a city in America have less of a chance of reaching 65 than a man in Bangladesh. When you look at that figure and you look at crack and you look at AIDS, you have to say to yourself, that it is not 65 anymore, it is somewhere around 40, and as I let my sons go out in the morning to go to school from 142nd street where we reside in Harlem, I am very afraid that those statistics are much too close to my household. One in every 60 babies in Manhattan in 1988 were born HIV infected, and the picture gets worse when you look to some sections of the South Bronx where it is 1 in every 44.

All these women that delivered these babies are not intravenous drug abusers. They are not presently having a relationship with an intravenous drug abuser. Some of them got diagnosed because their children were born and were ill. They are just not really clear on where this is coming from.

When you look at our surveillance for AIDS, more and more of the number of women claim not to know exactly where the disease comes from, that number rises all the time. In one of our hospitals in Brooklyn, Kings County, about 2 weeks ago, the doctors just walked out. They walked out for very serious reasons. They had 38 people in the emergency room waiting for a bed for over 5 days with chronic illnesses, and they could not place them.

Now, that is unbelievable, and that should be just a picture of what is going on in the hospitals in the city of New York, and this, in some cases, is where the people have to go to get their AZT. So the priorities here around this disease are a real problem.

There are some serious barriers. This disease is a heterosexual epidemic in our communities, and we know that there are gay and bisexual men of color, but we know this is a heterosexual disease because the children are infected. I mean, it has got to be heterosexual if the children are infected and dying.

Actually, to even be more graphic about what is happening, again, we probably are the primary agency that is examining behavior among all our people across the board in New York City. Our crack houses are flowing with adolescents who are part of something they call head banks. It means that these beautiful young girls come in and deposit their bodies in the hands of these chieftains of the crack house, and the chieftains, the people who

head the crack house make them perform oral and vaginal sex with these clients for payment of the crack at about $2 an act for sometimes 12 to 14 hours a day.

Now, as a result of this and among the various committees of medical doctors, black medical doctors that we have on the commission, there has been reported a wide increase of gonorrhea of the throat among adolescents in some of our communities.

We know that that goes along with other sexually transmitted diseases, and we know there is a connection between crack and AIDS, and it is the connection of payment of the drug with sex, and we know based on this and several other things going on in our community that we are absolutely losing this war.

And though we have pulled together, this fantastic commission, a coalition of the brightest and the best in the communities of color, I don't know how long it is going to be expected for them to be there without any money and any clear understanding of where we are going to go from this point.

When this disease first presented itself in New York, it was present in the back pages of the New York Times, and it was called a GRIDD, talked about gay and bisexual men dying and succumbing to these strange cancers and pneumonias. Now, GRIDD, for the most part, stood for the gay-related immune deficiency disease, and we have been criticized ever since in communities of color for not coming forward to this epidemic fast enough.

Well, we are here. We virtually just got the message, and we got it not just from Koop, who told us in about 1985, maybe you need to start looking at this thing because it looks like it is going to hit people of color, and we had to listen to that because the last thing we had heard from him was a message on a cigarette pack, so we figured that it must have been important, but not just from him, but we saw the death rate in our people.

Our ministers were burying countless numbers of young men and then young women and children that they saw coming into their churches looking the same way, with the same sort of ashiness, and the same strangeness, and distance as they lay in that casket. And we knew there was going to be a critical thing that was going to affect our children, and at this point they are hardly able to bury them anymore.

They are being stacked up at the door. Now, we can't continue to do this alone, so we are going to have to hold everybody that we can. I mean, this is the leadership of the city of New York, and we are struggling to just hold it together. We are going to have to hold everybody responsible.

We are going to have to get more resources in communities of color for prevention and treatment and research. We need to be involved in these clinical trials. When there was a question earlier today, about whether or not the scientists need more money, of course they need more money.

We sat there for 2 days and saw how some of the trials are not being conducted because they will be too expensive. Well, I would like to see some trials that include people of color, a large number of people of color, so I can feel real, real comfortable in going back to my community and telling them, go ahead on AZT. Take it. It is

going to keep you alive, hopefully, long enough for us to find a cure for this disease.

Now, I can't say that with the same comfort as other people can say that to other parts of the infected community, and that is the problem, and it is a problem that we are going to have to deal with. We give money to people who have natural disasters where they lose their properties and their homes all the time.

Well, now we have got a situation in communities of color, particularly in New York City, and I am saying in New York. I know it is happening in Chicago because one of the scientists jumped up in a meeting today and said help me get access to the communities of color because they are not listening to me. And if they don't listen to me, they are going to die.

So I know that it is happening everywhere else, and as I sit sometimes in my living room and look out the window and I see these cars coming through my neighborhood to purchase drugs, and they come through my neighborhood with license plates from Connecticut and all over the place where people feel that they are not going to be infected or affected by this situation, I shudder to think what is going on when you go back into those suburbs and how many people there who have private doctors and are not really being listed anywhere are actually a part of the infected community, so I caution people not to be so comfortable with what they see and say, well, it may be only the gays or it may be only people of color.

In either case it might not be so bad because, as we lose this war, everybody loses this war. If AIDS is a heterosexual disaster in every one of these communities that you go into, and we don't have the ammunition to fight it square on, we are going to be in a world of trouble, and that means of all us.

The President's budget does not reflect what is going on in our crack houses, what is going on in the closing of our hospitals. There is a world of difference, and what is being recommended is money, and the reality—I hear people giving figures, but I know that a lot of the figures that I hear, even in New York, and I am closer to the figures in New York, have to do with the care and treatment and the education of single men.

Now, we are talking about the possibility of 50,000 to 75,000 orphan infants in the next 3 years in New York City as a result of this disease. So you are no longer talking about single men who are infected. You have to take that money and times it by the number of children in that house to understand what it is really going to cost to make an effect with education and prevention and those sorts of things in this disease.

Let me give you just one small example.

Mrs. BOXER. Then, if you could, sum it up because I think you have given us a tremendous amount of information.

Ms. FRASER-HOWZE. Sure. Just one small example, and I am about to close. A woman called the other day, and she was in distress. She has full-blown AIDS and she is incapacitated. She is the mother of seven. She has a homemaker that comes to take care of her, but the homemaker is not assigned to the family, not assigned to the household. She is assigned to her as an individual because the system has been structured that way.

So her children sit and watch this homemaker take care of their dying mother, and at the same time the homemaker is not supposed to be allowed to help cook dinner for these seven children. Now, there is something wrong with that system, and if there is something we can do with our education, money, and resources, we need to do to fix it, we need to because what is happening is that in that crisis, the war is going to be one, but it is not going to be one by the affected communities that have this disease.

It is going to be one by the disease. Thank you.

[The prepared statement of Ms. Fraser-Howze may be found at end of hearing.]

Mrs. BOXER. Well, that was absolutely compelling testimony, and I am glad that you are here today.

Just so you know, next week we are going to be looking at the pediatric AIDS situation and the way to reach out to these children, which is, of course, through the family, and whatever family means in different communities, it means; and we separate that, and we deal with that. And I think as a result of your testimony today, which has really been very important because, frankly, all the years that we have held these hearings, we haven't heard from you. We haven't heard from people of color. This is the first year, I think, where we really have this compelling testimony to work with.

It is very, very important. I think after we have this panel finished and we go into the pediatric panel, this Committee will be better equipped to make decisions.

Let me just assure you, and I just want to ask this question, in terms of the trials at this time, is it still the case that people of color and women are not being used in the trials for AZT, to your knowledge?

Ms. FRASER-HOWZE. Yes, for the most part. They are represented in some of the trials, but in every trial that they are represented in, they are not represented in large numbers. The majority of people in the trial are, of course, gay men, and the majority of them gay white men. There is a real concern around it.

I am not going to go back to the community and tell them not to access AZT when they can because the trials don't represent you. I am just going to go back and tell them to do it and pray to God that there is going to be no differences when they get treatment.

Mrs. BOXER. I want to make a point here in terms of the gay men and the contribution they have made to science because the gay men were out there on all these experimental drugs when it wasn't easy to get people to come forward, so I want to make that point clear.

Ms. FRASER-HOWZE. I would like to reemphasize that——

Mrs. BOXER. I don't like to see us throw a wedge because we are all in this together, and I think the contribution of the gay men to the knowledge we have—but your point is very well taken that at this point we really do need to expand these trials, and I would be glad to look into this.

I would make a further point that with children, for example, we know even less.

Ms. FRASER-HOWZE. Much less. It is terrible.

Mrs. BOXER. And about women, so we really are at a point in this disease where we need to target and move on and accelerate, and it is absolutely crucial, because if we can find out, for example, how to stop the transmission from mother to child, we will stop this baby cold, and it is going to take research to do that.

So I think your being here is very important, and I urge you, because you are very articulate, to stay in this fight until we win it, not the disease. I think it is key.

Mrs. BOXER. Marie St. Cyr-Delpe, executive director of Women and AIDS Resource Network, we welcome you. We will be happy to hear your testimony.

STATEMENT OF MARIE ST. CYR-DELPE, EXECUTIVE DIRECTOR, WOMEN AND AIDS RESOURCE NETWORK, BROOKLYN, NY

Ms. ST. CYR-DELPE. Thank you, Congresswoman Boxer.

On behalf of the Women and AIDS Resource Network in Brooklyn, NY, I am pleased to present my views on the needs for AIDS education, prevention, research, and treatment to the Task Force on Human Resources. While I serve as executive director of WARN, I am also Commissioner at the Black Leadership Coalition on AIDS.

WARN, which stands for Women and AIDS Resource Network, was created in 1986 to respond to the unmet needs of women in New York City. Since that time, we have witnessed alarmingly increasing numbers of women who are getting diagnosed.

To give you any sense of WARN, we are currently four staff, and we began in 1987 with 27 women who were diagnosed. In 1988, we had 89 women, and in the close of 1989, we served 112 women. We expect that that number will double in the coming year. These women have an average of 2.7 children at the time they come to us, whether they come with a pregnancy or with a delivery. They come to us with this number of children before dealing with HIV.

Over 300 youngsters are involved in our client population. At this point maybe half of them already have suffered, have been an orphan, either because of one parent or two parents that are dying of AIDS.

Lately, our concerns are intensified as we encounter multiple diagnoses among siblings. In one particular family, let me share the story of the 61-year-old mother with you who faced the HIV positivity of three of her children in a 4-month time period. For the 26-year-old daughter, the first diagnosed, early intervention, clinical trials, or alternative drugs were not available until after her first bout with pneumocystis carinii pneumonia. With our intense education intervention in the family and with that woman and bringing information to the family, the other two siblings will have a chance at a better health outcome with early interventions through medical therapies and psychosocial support.

I share this case to pave the way to the following proposal.

Early intervention has to be redefined. Today it is defined as a means to access drugs like AZT, pentamidine, and bactrim, monitoring, and some primary care. Important as these things are, early intervention must be redefined to encompass efforts undertaken before the individual becomes infected. Meaningful behavior inter-

vention and prevention activities must become the starting point of early intervention and not the test.

In the history of the HIV epidemic, we as a nation have reacted to each group shown in the surveillance data diagnosed with AIDS—gay white men, intravenous drug users, babies, and now women—we maintain a crisis-oriented approach along with the traditional curative approach to health care. The incubation period of HIV virus renders this obsolete and dangerous as a methodology.

Without a cure or a vaccine, prevention efforts must be aggressive and targeted, and the commitment to them must be national, if not global, in scope.

The client population whose needs WARN addresses are very often the last to receive services, and that includes access to information, options to participate in clinical trials, and therapies.

Who are these women? Who are these families? Over 75 percent black and Latino women who live for the most part in Brooklyn, in Manhattan, in poor disenfranchised communities with the least resources, believe me, to sustain the burden of HIV and AIDS.

Our communities are in need of localized prevention efforts which encompass and take into consideration traditional modalities and institutions effective and credible among the population. The church, the church programs, the schools, the grassroot community groups, the neighborhood, and above all, the local leadership and the family members.

My concern is that in embracing early medical intervention, we give up or reduce to minimal the prevention efforts and the allocation of resources for the continuum of psychosocial support needs of those tested and still asymptomatic and more particularly those who are not yet infected.

In the neighborhoods where I am working, I am appalled, and you, Madam Chairwoman, may be frightened at the youth scene. Babies are having babies. You see nothing that makes their lives worthwhile. The schools are inadequate, their family life is fragmented, their sidewalks are permanently leased to drug dealers, and in their school yards crack and ice are the offered recreational stimulants. They are losing siblings and parents to violence, to many other diseases, and now to AIDS. What was a desperate situation has been made so much worse.

Ladies and gentlemen, we have to only take one look at the increasing rate of sexually transmitted disease, the rate of teen pregnancy, the unwanted pregnancies, the teenage runaway and the associated sexual activities, the increase in crack use despite the war on drugs, lack of drug treatment slots, the absence of drug treatment for mothers and their children, the sexual activities associated with drug use. If we take a look at that, we will realize that we are at the very beginning of prevention efforts in the United States to combat HIV. Each of these other societal ills functions as a very powerful cofactor in the transmission of this new disease.

In our clearinghouse of information, the age of concerned callers range between 13 years old and 68 years old. Increasingly, those who seek information are less and less representative of the stereotype that we have assumed for women who are at high risk of HIV infection. These people, while calling, remind me of the large numbers of women and men in recovery. They remind me of the sexual

adventurers of the 1970's and of the perception in the early 1980's that women were beyond the grasp of HIV. They remind me that in educational prevention, the very false underlying assumption was that people will make logical deductions and act accordingly to prevent infection and transmission of HIV.

We face today a sense of complacency and disregard to HIV and AIDS, particularly among those who feel they do not fall under a risk category or those who may have experiences which increases the risk yet they are so overwhelmed with trying to survive with AIDS that AIDS is the last issue on the list. I am referring to those who are homeless, who may be sick with addiction and others who are living on the borderline.

There is a great urgency, I believe, around establishing a comprehensive prevention and treatment agenda. But to be successful the approach must englobe other human needs before and beyond HIV. If not, then we make a conscious or at best unacknowledged decision to lose these lives. A collaborative effort and partnership between the local service providers and consumer groups, local and state governments, and decisionmakers like yourself is essential to making a true difference in our communities.

Essential in maximizing utilization of therapies is that we integrate a continuum of service in our delivery. The notion of treatment of HIV includes an array of medical approaches which compels us to add clinical trials, unconventional therapies to the treatment options. The reality is that treatment options are not available unilaterally. Minority populations, women, have had minimal access and in some neighborhoods, like Brooklyn, no access to clinical trials.

Underfunded community-based organizations, privately supported community-based organizations like WARN continue to appeal to city, state, and Federal funders to develop appropriately modeled services, specific to local neighborhoods, which impart a sense of proprietorship and responsibility to make and support changes in their own environment.

Ten years of prevention efforts, however underfunded, have forced us to discard the assumption that fear of death will compel behavior changes. A fragmented prevention strategy has sought to minimally educate targeted population groups among which an escalation of AIDS diagnosis continues that can hardly be said to have been effective. This is not an indictment of the methodologies. They have simply been too underfunded and too fragmented. They have also not allowed for the type of ongoing support that can sustain behavior changes.

Why? Because there has been no national commitment to prevention. What we really need is to urge you to embrace a prevention agenda so that we won't have to face the lives shattered and lost, and the cost to this country, and my neighborhood and in my family. A national prevention strategy is in order. If it is good and effective, it will also be costly, but not as costly as it will be if such an agenda is neglected.

Your input is needed to formulate such strategy and allocate resources to make it a reality. If you are thinking not the whole nation and if others are thinking not the whole nation needs the prevention effort, I would like to say that we have to think again.

Failure to educate and promote real behavior change through targeted education will threaten the future of us all, not just those who happen to live in the boroughs like Brooklyn and walk into my office.

Thank you, Madam Chairman.

[The prepared statement of Ms. St. Cyr-Delpe may be found at end of hearing.]

Mrs. BOXER. Last but certainly not least, someone who is responsible for this whole day of hearings, Jean McGuire, the National Organizations Responding to AIDS.

STATEMENT OF JEAN F. McGUIRE, CHAIR, NATIONAL ORGANIZATIONS RESPONDING TO AIDS (NORA)

Ms. MCGUIRE. Thank you, Madam Chairman. My testimony has been submitted for the record. There are just two or three kinds of summative points I would like to make.

First of all, I can't possibly paint a more graphic picture of the need than what you have painted for you today, and I am hoping you will share the passion as well as the substance that people have brought to the committee today with the other members as they enter into their deliberations.

I think what we are very clear about is that the great needs you have heard discussed today are going to require aggressive plans for action and substantial allocations of resources. Neither of these is available in the AIDS budget that the Administration has proposed.

However, responsive elements of a comprehensive plan are certainly contained both in the disaster relief proposal that Senators Kennedy, Hatch and others today proposed on the Senate side as well as in the early intervention initiative that Congressman Waxman has put forward here in addition to these. I have to say, frankly, I am quite amazed that it wasn't just this panel that you heard from in terms of the need for prevention while you look at care, there is an absolute need for a commitment and an expansion around targeted prevention activities.

But to be effective, all of these proposals must be well-funded. Otherwise, they will be symbolic rhetoric, and I think the women that are here today have told you they don't need any more of that. To ignore the urgency of the need will be to bargain for considerably greater loss in the future.

The National Organizations Responding to AIDS is currently having its member agencies reviewing our draft document for appropriations and budget consideration this year. It will be to your committee certainly by the end of the next 2 weeks, if not before. (See attachment.)

We will be proposing well over $1 billion in excess of the President's budget this year. We do not consider that to be a mark that is not needed. Certainly, you have had the need described well here today.

Frankly, this Administration proposed to the President a year ago that they would be at or above $2 billion by this time, so we have an Administration that has ignored its own internal assess-

ment of the need and continues to not be willing to confront the reality that we know is going on in the streets.

The resources that we will be looking to see increased will definitely be targeted around the early intervention and impact aid initiative you discussed as well as expansion in the prevention arena.

I would also say, and my testimony notes, particularly since there wasn't anybody that was here to particularly focus on research, that also was a trail that went through all of the testimony today.

How much we are able to do now is directly dependent on how good the Congress has been in that arena so far. We look for expanded research resources to both target efforts like the community-based research initiative efforts regarding the greater inclusion of women and minorities, as well as the greater expansion of pediatric focused trials, and additional treatment research into the opportunistic infections which has been lagging far behind the antiviral research that has undertaken.

We will be giving you hard and tough numbers for those things. I guess what I want to leave you with at the end of today is that none of our proposals count, and none of the descriptions of their lives count if this committee can't state a mark that is going to be something that can frame at appropriations process as we go into the ongoing deliberations this year.

I welcome you to come back to us and tell us what else you need us to do with your colleagues to make that a reality.

[The prepared statement of Ms. McGuire, with attachment may be found at end of hearing.]

Mrs. Boxer. Thank you very much Ms. McGuire.

Let me say that I have done it every year. I have brought the number back, it has always been higher, it has always been tougher. and I think this year as a result of your help, Jean, and Bill Baily and Tom Sheridan, who worked so hard to get us all these incredible witnesses, and it was really quite an astounding hearing, I have been around here 8 years and I think this was the best I have seen on an issue in terms of diversity of the people, the encompassing nature of their testimony, and the emotionalism but yet the facts, so I am overwhelmed at the end of this hearing, and I will take this back.

Many of the Members were here earlier, and that is very good, but we had everybody from a movie star who really gave up her privacy to come out here and talk to us, I thought, very directly about what we need to do to the mayor of the largest city in this country who came out and told us what we have to do, to the Members of Congress who have taken the leadership in this issue since we really started this fight to men and women and people of color and people on the frontline and doctors and social workers and activists.

I think it has just been a superb experience for me to sit here. I guess I have to tell you that this debate is part of a large debate that goes to the priorities of this Nation.

As all of you have spoken and there were many threads in your testimony dealing with other problems that come with AIDS, such as the homelessness and the despair, the lack of education, the

children having children and all the things that we know, a health care system that is bending and close to crumbling in some areas.

The bigger debate is what are we as a Nation and where are we going, and I think that the Chairman touched on it when he talked about a golden opportunity in history that we have now with changes in the world finally begin to end this decade of neglect and look at what our problems are in the face.

Under Ronald Reagan really it was the happy days, and we didn't want to see, and it took one of his friends getting AIDS before he even would mention the word. Now, we are looking and we are seeing a society that is really a dual society, as Mario Cuomo has stated, two cities, one glittering on the hill and the other one that is suffering, so George Bush has taken a look at this other city, and the question is, is he going to move us as a Nation to bring us all together and make sure we are one country where we care about each other, where we move forward, where we make the investment in our people.

Of course, I am always hopeful, that is why I am in this business because the day I lose hope I won't be, I was hopeful about a month ago in the Wall Street Journal had a whole summit on how we are failing in our educational system in this country and how it is beginning to bring us down as a Nation and make us not able to compete in the world today, and when I see that happening, when I see our business leaders understand that the problems that we have are directly related to our power as a nation and our ability to compete and the rest, and if they were here, these business leaders, they would be shocked, I think, at what is happening to their work force because if kids drop out of school and if they have babies at young ages and if they are on crack, they are not going to be able to join the work force.

If we are a sick population, we are not going to have a work force. If our cities are so congested that you can't even move an automobile a foot, we can't function, so I want to just thank you so much because your testimony here today was more effective than you think. It was not only a statement on what we need to do about AIDS, but to me it is yet another signal that the time has come for us to begin to reverse directions, so from the bottom on my heart I say thank you.

I know you waited a long time, this last panel, 4 hours. I know you sat through the entire hearing, but I don't think that was a waste of your time. I think that you realize that this Task Force is looking hard, so with that, the Task Force stands adjourned.

[The following additional information was supplied for the record:

PREPARED STATEMENT OF HON. NANCY PELOSI

MADAM CHAIRMAN, THANK YOU FOR THE OPPORTUNITY TO PRESENT MY VIEWS ON THE ADMINISTRATION'S 1991 PROPOSED BUDGET. I RECOGNIZE THE CHALLENGING TASK THIS COMMITTEE HAS BEFORE IT IN DETERMINING THE SPENDING PRIORITIES OF OUR COUNTRY AND APPRECIATE YOUR LEADERSHIP AND ATTENTION TO THE STAGGERING PROBLEM OF AIDS.

MADAME CHAIR, AND MEMBERS OF THE COMMITTEE, THE ADMINISTRATION'S 1991 AIDS BUDGET DEMONSTRATES A MAJOR LACK OF UNDERSTANDING AND LEADERSHIP. IT SHRINKS FROM THE NEW CHALLENGES AND RETREATS TO OLD PROGRAMS WHICH DO NOT MEET THE NEW NEEDS.

AS YOU ARE AWARE, THE ADMINISTRATION IS PROPOSING THAT AIDS SPENDING GO FROM $1.53 TO $1.69 BILLION FOR AIDS-RELATED ACTIVITIES AT THE PUBLIC HEALTH SERVICE (PHS). THIS REPRESENTS A REAL INCREASE OF ONLY 2.4%.

MADAM CHAIRMAN, I ASK UNANIMOUS CONSENT TO SUBMIT FOR THE RECORD CHARTS DEMONSTRATING THE PROFESSIONAL JUDGEMENT REQUESTS BY AGENCY WITHIN THE PUBLIC HEALTH SERVICE AND HOW THESE NEEDS ASSESSMENTS WERE IGNORED BY OMB IN REACHING THE FINAL FIGURES. THESE ESTIMATES OF NEED DO NOT COME FROM OUTSIDE ADVOCATES, THESE REQUESTS COME FROM THE ADMINISTRATION'S OWN SCIENTISTS,

PHYSICIANS AND PUBLIC HEALTH EXPERTS.

FOR ALL THE PHS AGENCIES THE PROFESSIONAL JUDGEMENT REQUESTS TOTALLED $3.1 BILLION OR NEARLY TWICE THE OMB FIGURE OF $1.69 BILLION.

ARE WE DOING ALL WE CAN AS A NATION TO RESPOND TO THE PUBLIC HEALTH THREAT OF THE CENTURY? THE ANSWER IS AN EMPHATIC NO!. THE ADMINISTRATION'S BUDGET INDICATES A WILLINGNESS TO DO ABOUT HALF OF WHAT WE CAN AND SHOULD DO.

IN REGARD TO A VACCINE OR CURE, DR. FAUCI, WHO HEADS THE AIDS RESEARCH EFFORTS AT NIH, IS SCHEDULED AT ONLY 59% OF WHAT HE REQUESTED TO CONDUCT AIDS-RELATED RESEARCH.

SCIENTISTS TELL US THAT THERE ARE MANY NEW DRUGS WORTHY OF CLINICAL TRIALS. THE ONLY LIMITATION IS THE FUNDING FOR THIS RESEARCH. THE PRESIDENT'S PROPOSED BUDGET MEANS THAT PLANS TO EXPAND ONGOING CLINICAL TRIALS AND INITIATE NEW TRIALS WILL BE SUSPENDED. INITIATIVES FOR RESEARCH CENTERS, RESEARCH TRAINING, DRUG DEVELOPMENT AND VACCINE DEVELOPMENT WILL BE SUSPENDED. INITIATIVES TO GIVE EMPHASIS TO UNDERREPRESENTED AND MINORITY GROUPS WILL BE SUSPENDED.

ARE WE DOING ALL WE CAN AS A NATION TO PREVENT THE FURTHER TRANSMISSION OF HIV? AGAIN, THE ANSWER IS NO. FEDERAL AND STATE PREVENTION PROGRAMS LACK AN EMPHASIS ON INDIVIDUAL BEHAVIOR

CHANGE -- THE ONLY WAY TO STOP THE SPREAD OF THE VIRUS. DEMONSTRATION OUTREACH PROGRAMS SPONSORED BY THE NATIONAL INSTITUTE ON DRUG ABUSE HAVE CLEARLY DEMONSTRATED THAT AN AGGRESSIVE OUTREACH PROGRAM CAN GREATLY REDUCE HIV TRANSMISSION. THE RESULTS FROM THESE 63 PILOT PROGRAMS ACROSS THE COUNTRY GIVE US HOPE. YET, THIS BUSH BUDGET PROPOSES TO ZERO OUT THE PROGRAM. AS INCREDIBLE AS IT MAY SEEM, THESE OUTREACH PROGRAMS -- WHICH ARE LITERALLY HOLDING BACK A NEW WAVE OF HIV INFECTION -- ARE SCHEDULED TO BE PHASED OUT WITH NOTHING PROPOSED TO REPLACE THEM.

ARE WE DOING ENOUGH TO CARE FOR PEOPLE WITH AIDS AND HIV-DISEASE? AGAIN, THE ANSWER IS NO -- BUT EVEN WORSE, THE ADMINISTRATION HAS DECIDED AS A MATTER OF POLICY THAT THE PUBLIC HEALTH SERVICE SHOULD NOT BE INVOLVED IN PATIENT CARE -- NOT EVEN IN AN EPIDEMIC. THIS DECISION, IN TURN, HAS LED TO A MAJOR SHIFT IN PRIORITY WHICH GOES DIRECTLY AGAINST LOGIC REGARDING WHAT NEEDS TO BE DONE AT THIS POINT IN THE EPIDEMIC. IT ALSO RUNS AGAINST THE DIRECTION STRONGLY RECOMMENDED BY THE NATIONAL COMMISSION ON AIDS AND THE PRESIDENT'S COMMISSION ON THE HIV EPIDEMIC WHICH PRECEDED IT.

WHILE THE BUDGET ASSUMES AN INCREASE OF 30% IN THE NUMBER OF NEW AIDS CASES, DISCRETIONARY SPENDING FOR AIDS-RELATED PATIENT CARE AND SERVICES WOULD BE DECREASED BY 35%. THE HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA) REQUESTED $167 MILLION FOR AIDS-RELATED SERVICES; OMB GAVE THEM $33 MILLION OR ONLY 20% OF THEIR REQUEST.

ENTIRE PROGRAMS FOR HOME HEALTH SERVICES AND AIDS DRUG REIMBURSEMENT FOR LOW INCOME PEOPLE WERE ELIMINATED. ENTIRE PROGRAMS FOR AIDS-RELATED COUNSELING AND MENTAL HEALTH SERVICES AND FOR EARLY INTERVENTION PROJECTS WERE ELIMINATED. ENTIRE PROGRAMS FOR SUBACUTE CARE, ORAL HEALTH CARE, AND HEALTH CARE PLANNING WERE ELIMINATED. THESE PROGRAMS ADDRESSED THE MOST PRESSING NEEDS AT THIS POINT IN THE EPIDEMIC. I WOULD LIKE TO EMPHASIZE THAT THE ADMINISTRATION IS NOT PROPOSING TO REDUCE THE FUNDING FOR THESE PROGRAMS -- THEY ARE PROPOSING TO ELIMINATE THEM ENTIRELY.

THE ONLY CLEAR POLICY TO EMERGE FROM THIS BUDGET IS THAT THE FINANCING OF HEALTH CARE IS NOT A FEDERAL RESPONSIBILITY. CLEARLY, CONGRESS MUST ASSERT THAT MANAGING THE COSTS ASSOCIATED WITH THIS EPIDEMIC MUST BE A RESPONSIBILITY SHARED BY ALL LEVELS OF GOVERNMENT -- LOCAL, STATE, AND FEDERAL.

MADAME CHAIR, WE WERE BOTH PRESENT WHEN OMB DIRECTOR DARMAN GAVE HIS DISTRESSING TESTIMONY BEFORE THE GOVERNMENT OPERATIONS COMMITTEE LAST YEAR. FOLLOWING HIS APPEARANCE, HE ASKED TO BE JUDGED ON THE FY 1991 BUDGET AND NOT THE BUDGET HE INHERITED FROM THE REAGAN ADMINISTRATION.

THE NEW JUDGEMENT IS IN. THIS IS THE WORST AIDS BUDGET IN AT LEAST FIVE YEARS. IT NOT ONLY SETS AN ARBITRARY SPENDING LIMIT THAT IS UNREALISTIC -- IT ALSO GOES TO IDEOLOGICAL EXTREMES TO

ELIMINATE PROGRAMS THAT ACTUALLY HELP PEOPLE WITH AIDS. IT WOULD SHIFT FUNDING FROM EFFECTIVE PREVENTION PROGRAMS TO ONES WHICH DO NOT WORK. IT WOULD SUSPEND GROWTH IN RESEARCH TO FIND A CURE.

THE ADMINISTRATION HAS FAILED TO SEND US A REASONABLE BUDGET REQUEST -- CONGRESS MUST DO BETTER.

THE HIGHEST POSSIBLE FIGURE MUST BE ESTABLISHED FOR THE HEALTH FUNCTION SO THAT THE EMERGING PRIORITY ISSUES -- IMPACT AID TO HARD HIT METROPOLITAN AREAS AND EARLY INTERVENTION PROGRAMS TO TREAT PEOPLE EARLY IN THE DISEASE PROCESS -- CAN BE FUNDED. CUTS IN SPENDING FOR BASIC RESEARCH AND PREVENTION EFFORTS MUST BE STOPPED.

MADAM CHAIRMAN, THANK YOU FOR THE OPPORTUNITY TO PRESENT MY VIEWS ON THE PRESIDENT'S PROPOSED BUDGET. I COMMEND YOU AND THE COMMITTEE FOR ALL THAT YOU ARE DOING TO REASSESS THE MANY PRESSING NEEDS OF OUR COUNTRY. I WISH YOU GREAT SUCCESS.

February 23, 1990
MK29 WHOJOHN.WK1

PUBLIC HEALTH SERVICE
HIV/AIDS
(dollars in thousands)

PUBLIC HEALTH SERVICE	FY 1991 Request to PHS	FY 1991 PHS Request to HHS	FY 1991 HHS Request to OMB	FY 1991 Pres. Budget
I. Basic Science Research	$1,240,095	$986,803	$847,995	$807,232
II. Risk Assessment and Prevention	1,391,173	857,326	756,150	729,437
III. Product Evaluation, Research, and Monitoring	101,481	91,726	64,568	63,236
IV. Clinical Health Services Research & Delivery	249,464	188,284	69,067	72,952
V. PHS-wide Activities	117,418	55,420	22,220	22,035
PHS TOTAL	$3,099,631	$2,179,559	$1,760,000	$1,694,892

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PUBLIC HEALTH SERVICE
HIV/AIDS
(dollars in thousands)

	FY 1991 Request to PHS	FY 1991 PHS Request to HHS	FY 1991 HHS Request to OMB	FY 1991 Pres. Budget
FOOD AND DRUG ADMINISTRATION	$101,481	$91,726	$64,568	$63,236
HEALTH RESOURCES AND SERVICES ADMINISTRATION	241,500	183,284	68,165	72,679
INDIAN HEALTH SERVICE	2,249	2,249	1,091	1,013
CENTERS FOR DISEASE CONTROL	1,134,570	630,367	530,889	509,103
NATIONAL INSTITUTES OF HEALTH	1,278,409	997,780	836,189	800,164
ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION	277,616	250,363	238,545	229,669
AGENCY FOR HEALTH CARE POLICY AND RESEARCH	20,100	14,452	11,715	10,505
OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH	43,706	9,338	8,838	8,523
PHS TOTAL	$3,099,631	$2,179,559	$1,760,000	$1,694,892

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PUBLIC HEALTH SERVICE
HIV/AIDS
(dollars in thousands)

PUBLIC HEALTH SERVICE	FY 1991 Request to PHS	FY 1991 PHS Request to HHS	FY 1991 HHS Request to OMB	FY 1991 Pres. Budget
I. Basic Science Research				
A. Biomedical Research	$369,636	$307,623	$237,541	$212,922
B. Neuroscience & Neuropsychiatric Research	77,464	59,633	45,017	40,783
C. Behavioral Research	155,681	130,507	126,985	125,889
D. Therapeutic Agents	453,391	367,110	355,597	326,388
E. Vaccines	125,723	104,254	69,446	86,130
F. Research Enhancement	58,200	17,676	13,409	15,120
subtotal	1,240,095	986,803	847,995	807,232
II. Risk Assessment and Prevention				
A. Surveillance	141,096	114,619	120,333	110,834
B. Population-Based Res: Nat Hist, Trans, Risk Factors	266,644	215,686	202,124	197,216
C. Information & Education/Preventive Services	983,433	527,021	433,693	421,387
1. High Risk or Infected Persons (non-add)	(619,551)	(253,799)	(213,431)	(203,978)
2. Special Minority Initiatives (non-add)	(62,745)	(55,411)	(55,411)	(53,210)
3. School and College Aged Youth (non-add)	(76,179)	(72,912)	(55,313)	(53,293)
4. General Public & Special Programs (non-add)	(96,242)	(65,163)	(55,003)	(62,415)
5. Health-Care Workers & Providers (non-add)	(51,129)	(39,016)	(39,315)	(33,689)
6. Prevention Capacity Enhancement (non-add)	(77,587)	(40,720)	(15,220)	(14,802)
subtotal	1,391,173	857,326	756,150	729,437
III. Product Evaluation, Research, and Monitoring				
A. Therapeutic Agents	51,240	45,091	26,370	24,760
B. Vaccines	14,010	13,023	11,398	9,688
C. Diagnostic Reagents and Test Kits	13,131	13,288	10,626	10,227
D. Blood and Blood Products	14,000	11,818	10,018	9,150
E. Medical Devices	9,100	8,506	6,156	9,411
subtotal	101,481	91,726	64,568	63,236
IV. Clinical Health Services Research & Delivery				
A. Services	176,364	149,577	42,574	41,529
[Drug Subsidy Programs (non-add)	(30,000)	0	0	0
B. Health Services Demonstrations	20,000	15,000	8,341	14,735
C. Construction	30,000	6,173	4,173	4,129
D. Research	23,100	17,534	13,979	12,559
subtotal	249,464	188,284	69,067	72,952
V. PHS-wide Activities				
A. OASH/NAPO	4,018	4,570	4,070	3,935
B. Contingency Fund	25,000	0	0	0
C. Construction (PHS Facilities)	88,400	50,850	18,150	18,100
subtotal	117,418	55,420	22,220	22,035
PHS Total	$3,099,631	$2,179,559	$1,760,000	$1,694,892

February 23, 1990
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PUBLIC HEALTH SERVICE
HIV/AIDS
(dollars in thousands)

FOOD AND DRUG ADMINISTRATION	FY 1991 Request to PHS	FY 1991 PHS Request to HHS	FY 1991 HHS Request to OMB	FY 1991 Pres. Budget
I. Basic Science Research				
A. Biomedical Research	---	---	---	---
B. Neuroscience & Neuropsychiatric Research	---	---	---	---
C. Behavioral Research	---	---	---	---
D. Therapeutic Agents	---	---	---	---
E. Vaccines	---	---	---	---
F. Research Enhancement	---	---	---	---
subtotal	0	0	0	0
II. Risk Assessment and Prevention				
A. Surveillance	---	---	---	---
B. Population-Based Res: Nat Hist, Trans, Risk Factors.	---	---	---	---
C. Information & Education/Preventive Services	---	---	---	---
1. High Risk or Infected Persons (non-add)	---	---	---	---
2. Special Minority Initiatives (non-add)	---	---	---	---
3. School and College Aged Youth (non-add)	---	---	---	---
4. General Public & Special Programs (non-add)	---	---	---	---
5. Health-Care Workers & Providers (non-add)	---	---	---	---
6. Prevention Capacity Enhancement (non-add)	---	---	---	---
subtotal	0	0	0	0
III. Product Evaluation, Research, and Monitoring				
A. Therapeutic Agents	51,240	45,091	26,370	24,760
B. Vaccines	14,010	13,023	11,398	9,688
C. Diagnostic Reagents and Test Kits	13,131	13,288	10,626	10,227
D. Blood and Blood Products	14,000	11,818	10,018	9,150
E. Medical Devices	9,100	8,506	6,156	9,411
subtotal	101,481	91,726	64,568	63,236
IV. Clinical Health Services Research & Delivery				
A. Services	---	---	---	---
[Drug Subsidy Programs (non-add)	---	---	---	---
B. Health Services Demonstrations	---	---	---	---
C. Construction	---	---	---	---
D. Research	---	---	---	---
subtotal	0	0	0	0
V. PHS-wide Activities				
A. OASH/NAPO	---	---	---	---
B. Contingency Fund	---	---	---	---
C. Construction (PHS Facilities)	---	---	---	---
subtotal	0	0	0	0
FDA Total	$101,481	$91,726	$64,568	$63,236

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PUBLIC HEALTH SERVICE
HIV/AIDS
(dollars in thousands)

HEALTH RESOURCES AND SERVICES ADMINISTRATION	FY 1991 Request to PHS	FY 1991 PHS Request to HHS	FY 1991 HHS Request to OMB	FY 1991 Pres. Budget
I. Basic Science Research				
A. Biomedical Research	---	---	---	---
B. Neuroscience & Neuropsychiatric Research	---	---	---	---
C. Behavioral Research	---	---	---	---
D. Therapeutic Agents	---	---	---	---
E. Vaccines	---	---	---	---
F. Research Enhancement	---	---	---	---
subtotal	0	0	0	0
II. Risk Assessment and Prevention				
A. Surveillance	---	---	---	---
B. Population-Based Res: Nat Hist, Trans, Risk Factors.	---	---	---	---
C. Information & Education/Preventive Services	25,000	22,660	22,660	21,000
1. High Risk or Infected Persons (non-add)	---	---	---	---
2. Special Minority Initiatives (non-add)	---	---	---	---
3. School and College Aged Youth (non-add)	---	---	---	---
4. General Public & Special Programs (non-add)	---	---	---	---
5. Health-Care Workers & Providers (non-add)	(25,000)	(22,660)	(22,660)	(21,000)
6. Prevention Capacity Enhancement (non-add)	---	---	---	---
subtotal	25,000	22,660	22,660	21,000
III. Product Evaluation, Research, and Monitoring				
A. Therapeutic Agents	---	---	---	---
B. Vaccines	---	---	---	---
C. Diagnostic Reagents and Test Kits	---	---	---	---
D. Blood and Blood Products	---	---	---	---
E. Medical Devices	---	---	---	---
subtotal	0	0	0	0
IV. Clinical Health Services Research & Delivery				
A. Services	166,500	139,451	32,991	32,815
[Drug Subsidy Programs (non-add)	(30,000)	---	---	---
B. Health Services Demonstrations	20,000	15,000	8,341	14,735
C. Construction	30,000	6,173	4,173	4,129
D. Research	---	---	---	---
subtotal	216,500	160,624	45,505	51,679
V. PHS-wide Activities				
A. OASH/NAPO	---	---	---	---
B. Contingency Fund	---	---	---	---
C. Construction (PHS Facilities)	---	---	---	---
subtotal	0	0	0	0
HRSA Total	$241,500	$183,284	$68,165	$72,679

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PUBLIC HEALTH SERVICE
HIV/AIDS
(dollars in thousands)

INDIAN HEALTH SERVICE	FY 1991 Request to PHS	FY 1991 PHS Request to HHS	FY 1991 HHS Request to OMB	FY 1991 Pres. Budget
I. Basic Science Research				
A. Biomedical Research	---	---	---	---
B. Neuroscience & Neuropsychiatric Research	---	---	---	---
C. Behavioral Research	---	---	---	---
D. Therapeutic Agents	---	---	---	---
E. Vaccines	---	---	---	---
F. Research Enhancement	---	---	---	---
subtotal	0	0	0	0
II. Risk Assessment and Prevention				
A. Surveillance	100	106	106	95
B. Population-Based Res: Nat Hist, Trans, Risk Factors.	---	---	---	---
C. Information & Education/Preventive Services	1,300	1,329	714	650
1. High Risk or Infected Persons (non-add)	(100)	(106)	(106)	(50)
2. Special Minority Initiatives (non-add)	(300)	(317)	(317)	(315)
3. School and College Aged Youth (non-add)	(100)	(106)	(106)	(50)
4. General Public & Special Programs (non-add)	(200)	(200)	(106)	(100)
5. Health-Care Workers & Providers (non-add)	(100)	(100)	(79)	(50)
6. Prevention Capacity Enhancement (non-add)	(500)	(500)	---	(85)
subtotal	1,400	1,435	820	745
III. Product Evaluation, Research, and Monitoring				
A. Therapeutic Agents	---	---	---	---
B. Vaccines	---	---	---	---
C. Diagnostic Reagents and Test Kits	---	---	---	---
D. Blood and Blood Products	---	---	---	---
E. Medical Devices	---	---	---	---
subtotal	0	0	0	0
IV. Clinical Health Services Research & Delivery				
A. Services	849	814	271	268
[Drug Subsidy Programs (non-add)	---	---	---	---
B. Health Services Demonstrations	---	---	---	---
C. Construction	---	---	---	---
D. Research	---	---	---	---
subtotal	849	814	271	268
V. PHS-wide Activities				
A. OASH/NAPO	---	---	---	---
B. Contingency Fund	---	---	---	---
C. Construction (PHS Facilities)	---	---	---	---
subtotal	0	0	0	0
IHS Total	$2,249	$2,249	$1,091	$1,013

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PUBLIC HEALTH SERVICE
HIV/AIDS
(dollars in thousands)

CENTERS FOR DISEASE CONTROL	FY 1991 Request to PHS	FY 1991 PHS Request to HHS	FY 1991 HHS Request to OMB	FY 1991 Pres. Budget
I. Basic Science Research				
A. Biomedical Research	$6,916	$6,937	$6,937	$5,522
B. Neuroscience & Neuropsychiatric Research	---	---	---	---
C. Behavioral Research	5,300	---	---	---
D. Therapeutic Agents	---	---	---	---
E. Vaccines	---	---	---	---
F. Research Enhancement	---	---	---	---
subtotal	12,216	6,937	6,937	5,522
II. Risk Assessment and Prevention				
A. Surveillance	135,136	109,116	106,116	96,758
B. Population-Based Res: Nat Hist, Trans, Risk Factors	80,264	49,883	44,883	44,162
C. Information & Education/Preventive Services	906,954	464,431	372,953	362,661
1. High Risk or Infected Persons (non-add)	(608,397)	(246,235)	(205,735)	(200,146)
2. Special Minority Initiatives (non-add)	(57,681)	(50,326)	(50,326)	(48,307)
3. School and College Aged Youth (non-add)	(76,079)	(71,621)	(53,643)	(52,527)
4. General Public & Special Programs (non-add)	(87,710)	(56,029)	(48,029)	(46,964)
5. Health-Care Workers & Providers (non-add)	---	0	---	---
6. Prevention Capacity Enhancement (non-add)	(77,087)	(40,220)	(15,220)	(14,717)
subtotal	1,122,354	623,430	523,952	503,581
III. Product Evaluation, Research, and Monitoring				
A. Therapeutic Agents	---	---	---	---
B. Vaccines	---	---	---	---
C. Diagnostic Reagents and Test Kits	---	---	---	---
D. Blood and Blood Products	---	---	---	---
E. Medical Devices	---	---	---	---
subtotal	0	0	0	0
IV. Clinical Health Services Research & Delivery				
A. Services	---	---	---	---
[Drug Subsidy Programs (non-add)	---	---	---	---
B. Health Services Demonstrations	---	---	---	---
C. Construction	---	---	---	---
D. Research	---	---	---	---
subtotal	0	0	0	0
V. PHS-wide Activities				
A. OASH/NAPO	---	---	---	---
B. Contingency Fund	---	---	---	---
C. Construction (PHS Facilities)	---	---	---	---
subtotal	0	0	0	0
CDC Total	$1,134,570	$630,367	$530,889	$509,103

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PUBLIC HEALTH SERVICE
HIV/AIDS
(dollars in thousands)

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION	FY 1991 Request to PHS	FY 1991 PHS Request to HHS	FY 1991 HHS Request to OMB	FY 1991 Pres. Budget
I. Basic Science Research				
A. Biomedical Research	$35,123	$31,387	$29,887	$27,339
B. Neuroscience & Neuropsychiatric Research	30,446	27,345	22,491	19,114
C. Behavioral Research	143,068	129,530	121,030	120,717
D. Therapeutic Agents	---	0	---	---
E. Vaccines	---	0	---	---
F. Research Enhancement	5,589	5,118	4,566	5,675
subtotal	214,226	187,380	177,974	172,845
II. Risk Assessment and Prevention				
A. Surveillance	5,860	5,397	5,397	5,000
B. Population-Based Res: Nat Hist, Trans, Risk Factors	28,297	27,982	26,727	25,020
C. Information & Education/Preventive Services	15,568	15,560	15,221	14,704
1. High Risk or Infected Persons (non-add)	(1,130)	(1,120)	(987)	(986)
2. Special Minority Initiatives (non-add)	---	---	---	---
3. School and College Aged Youth (non-add)	---	---	---	---
4. General Public & Special Programs (non-add)	(3,740)	(3,740)	(3,740)	(3,685)
5. Health-Care Workers & Providers (non-add)	(10,698)	(10,700)	(10,494)	(10,033)
6. Prevention Capacity Enhancement (non-add)	---	---	---	---
subtotal	49,725	48,939	47,345	44,724
III. Product Evaluation, Research, and Monitoring				
A. Therapeutic Agents	---	---	---	---
B. Vaccines	---	---	---	---
C. Diagnostic Reagents and Test Kits	---	---	---	---
D. Blood and Blood Products	---	---	---	---
E. Medical Devices	---	---	---	---
subtotal	0	0	0	0
IV. Clinical Health Services Research & Delivery				
A. Services	9,015	9,312	9,312	8,446
[Drug Subsidy Programs (non-add)	---	---	---	---
B. Health Services Demonstrations	---	---	---	---
C. Construction	---	---	---	---
D. Research	3,000	3,082	2,264	2,054
subtotal	12,015	12,394	11,576	10,500
V. PHS-wide Activities				
A. OASH/NAPO	---	---	---	---
B. Contingency Fund	---	---	---	---
C. Construction (PHS Facilities)	1,650	1,650	1,650	1,600
subtotal	1,650	1,650	1,650	1,600
ADAMHA Total	$277,616	$250,363	$238,545	$229,669

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PUBLIC HEALTH SERVICE
HIV/AIDS
(dollars in thousands)

NATIONAL INSTITUTES OF HEALTH	FY 1991 Request to PHS	FY 1991 PHS Request to HHS	FY 1991 HHS Request to OMB	FY 1991 Pres. Budget
I. Basic Science Research				
A. Biomedical Research	$327,597	$269,299	$200,717	$180,061
B. Neuroscience & Neuropsychiatric Research	47,018	32,288	22,526	21,669
C. Behavioral Research	7,313	6,977	5,955	5,172
D. Therapeutic Agents	453,391	367,110	355,597	326,388
E. Vaccines	125,723	104,254	69,446	86,130
F. Research Enhancement	52,611	12,558	8,843	9,445
subtotal	1,013,653	792,486	663,084	628,865
II. Risk Assessment and Prevention				
A. Surveillance	---	---	8,714	8,981
B. Population-Based Res: Nat Hist, Trans, Risk Factors.	158,083	137,821	130,514	128,034
C. Information & Education/Preventive Services	19,923	18,273	17,377	17,784
1. High Risk or Infected Persons (non-add)	---	(6,338)	(6,603)	(2,796)
2. Special Minority Initiatives (non-add)	---	---	---	---
3. School and College Aged Youth (non-add)	---	(1,185)	(1,564)	(716)
4. General Public & Special Programs (non-add)	(4,592)	(5,194)	(3,128)	(11,666)
5. Health-Care Workers & Providers (non-add)	(15,331)	(5,556)	(6,082)	(2,606)
6. Prevention Capacity Enhancement (non-add)	---	---	---	---
subtotal	178,006	156,094	156,605	154,799
III. Product Evaluation, Research, and Monitoring				
A. Therapeutic Agents	---	---	---	---
B. Vaccines	---	---	---	---
C. Diagnostic Reagents and Test Kits	---	---	---	---
D. Blood and Blood Products	---	---	---	---
E. Medical Devices	---	---	---	---
subtotal	0	0	0	0
IV. Clinical Health Services Research & Delivery				
A. Services	---	---	---	---
[Drug Subsidy Programs (non-add)	---	---	---	---
B. Health Services Demonstrations	---	---	---	---
C. Construction	---	---	---	---
D. Research	---	---	---	---
subtotal	0	0	0	0
V. PHS-wide Activities				
A. OASH/NAPO	---	---	---	---
B. Contingency Fund	---	---	---	---
C. Construction (PHS Facilities)	86,750	49,200	16,500	16,500
subtotal	86,750	49,200	16,500	16,500
NIH Total	$1,278,409	$997,780	$836,189	$800,164

February 23, 1990
MK29 WHOJOHN.WK1

PUBLIC HEALTH SERVICE
HIV/AIDS
(dollars in thousands)

AGENCY FOR HEALTH CARE POLICY AND RESEARCH	FY 1991 Request to PHS	FY 1991 PHS Request to HHS	FY 1991 HHS Request to OMB	FY 1991 Pres. Budget
I. Basic Science Research				
A. Biomedical Research	---	---	---	---
B. Neuroscience & Neuropsychiatric Research	---	---	---	---
C. Behavioral Research	---	---	---	---
D. Therapeutic Agents	---	---	---	---
E. Vaccines	---	---	---	---
F. Research Enhancement	---	---	---	---
subtotal	0	0	0	0
II. Risk Assessment and Prevention				
A. Surveillance	---	---	---	---
B. Population-Based Res: Nat Hist, Trans, Risk Factors.	---	---	---	---
C. Information & Education/Preventive Services	---	---	---	---
1. High Risk or Infected Persons (non-add)	---	---	---	---
2. Special Minority Initiatives (non-add)	---	---	---	---
3. School and College Aged Youth (non-add)	---	---	---	---
4. General Public & Special Programs (non-add)	---	---	---	---
5. Health-Care Workers & Providers (non-add)	---	---	---	---
6. Prevention Capacity Enhancement (non-add)	---	---	---	---
subtotal	0	0	0	0
III. Product Evaluation, Research, and Monitoring				
A. Therapeutic Agents	---	---	---	---
B. Vaccines	---	---	---	---
C. Diagnostic Reagents and Test Kits	---	---	---	---
D. Blood and Blood Products	---	---	---	---
E. Medical Devices	---	---	---	---
subtotal	0	0	0	0
IV. Clinical Health Services Research & Delivery				
A. Services	---	---	---	---
[Drug Subsidy Programs (non-add)	---	---	---	---
B. Health Services Demonstrations	---	---	---	---
C. Construction	---	---	---	---
D. Research	20,100	14,452	11,715	10,505
subtotal	20,100	14,452	11,715	10,505
V. PHS-wide Activities				
A. OASH/NAPO	---	---	---	---
B. Contingency Fund	---	---	---	---
C. Construction (PHS Facilities)	---	---	---	---
subtotal	0	0	0	0
HCPR Total	$20,100	$14,452	$11,715	$10,505

February 23, 1990
MK29 WHOJOHN.WK1

PUBLIC HEALTH SERVICE
HIV/AIDS
(dollars in thousands)

OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH	FY 1991 Request to PHS	FY 1991 PHS Request to HHS	FY 1991 HHS Request to OMB	FY 1991 Pres. Budget
I. Basic Science Research				
A. Biomedical Research	---	---	---	---
B. Neuroscience & Neuropsychiatric Research	---	---	---	---
C. Behavioral Research	---	---	---	---
D. Therapeutic Agents	---	---	---	---
E. Vaccines	---	---	---	---
F. Research Enhancement	---	---	---	---
subtotal	0	0	0	0
II. Risk Assessment and Prevention				
A. Surveillance	---	---	---	---
B. Population-Based Res: Nat Hist, Trans, Risk Factors.	---	---	---	---
C. Information & Education/Preventive Services	14,688	4,768	4,768	4,588
1. High Risk or Infected Persons (non-add)	(9,924)	---	---	---
2. Special Minority Initiatives (non-add)	(4,764)	(4,768)	(4,768)	(4,588)
3. School and College Aged Youth (non-add)	---	---	---	---
4. General Public & Special Programs (non-add)	---	---	---	---
5. Health-Care Workers & Providers (non-add)	---	---	---	---
6. Prevention Capacity Enhancement (non-add)	---	---	---	---
subtotal	14,688	4,768	4,768	4,588
III. Product Evaluation, Research, and Monitoring				
A. Therapeutic Agents	---	---	---	---
B. Vaccines	---	---	---	---
C. Diagnostic Reagents and Test Kits	---	---	---	---
D. Blood and Blood Products	---	---	---	---
E. Medical Devices	---	---	---	---
subtotal	0	0	0	0
IV. Clinical Health Services Research & Delivery				
A. Services	---	---	---	---
[Drug Subsidy Programs (non-add)	---	---	---	---
B. Health Services Demonstrations	---	---	---	---
C. Construction	---	---	---	---
D. Research	---	---	---	---
subtotal	0	0	0	0
V. PHS-wide Activities				
A. OASH/NAPO	4,018	4,570	4,070	3,935
B. Contingency Fund	25,000	---	---	---
C. Construction (PHS Facilities)	---	---	---	---
subtotal	29,018	4,570	4,070	3,935
OASH Total	$43,706	$9,338	$8,838	$8,523

HEALTH RESOURCES AND SERVICES ADMINISTRATION
ACQUIRED IMMUNE DEFICIENCY SYNDROME
BUDGET AUTHORITY IN $000

	FY 1991 REQUEST TO OASH	FY 1991 PHS REQUEST TO HHS	FY 1991 HHS REQUEST TO OMB	FY 1991 PRES BUDGET
AIDS:				
Education and Training Centers	25,000	22,660	22,660	21,000
Community Health Care Services	36,000	21,525	13,405	13,323
HIV Health Services Grants	35,000	22,926	19,565	19,424
Grants to States for HIV Health Services and Planning	0	95,000	0	0
Pediatric AIDS Health Care Demonstration Grants	20,000	15,000	8,341	14,803
AIDS Drug Reimbursement Program	30,000	0	0	0
Oral Health Care for AIDS Patients	1,500	0	0	0
Demo Projects-Sub-Acute Care	7,500	0	0	0
Clinical Care/Model Protocol	6,000	0	0	0
Counseling & Mental Health Services	5,500	0	0	0
Formula Grants to States for Home Health Services	45,000	0	0	0
AIDS Facilities Renovation	30,000	6,173	4,173	4,129
Program Management	(12,450)	(6,000)	(4,125)	(4,850)
TOTAL, AIDS	241,500	183,284	68,165	72,679
(FTEs)	(102)	(88)	(55)	(55)

HRSA/DFM/BFPB
DW/15/WEJON91

PREPARED STATEMENT OF HON. HENRY A. WAXMAN

Let me begin by thanking you for holding these hearings and for allowing me this opportunity to present my suggestions to the Committee. You have shown real leadership on the problems the AIDS epidemic poses to the Nation, and I hope with this year's budget that we can begin to address some of those that are most pressing.

Over the past nine years, the country has gone through cycles of AIDS awareness: From ignorance to hysteria to complacency. We have gone from a time when no one knew of AIDS to a time when everyone was terrified of it to a time when everyone knows about it and most people are seemingly unconcerned.

This complacency is dangerous for public health policy on infection and treatment.

But such complacency is particularly dangerous for budget policy. We cannot short-change the epidemic. It is threatening the lives of hundreds of thousands of Americans. It is threatening the solvency of our public hospital system. It is threatening the adequacy of health care services to all Americans, infected and uninfected.

The President's budget is constructed as if these costs won't happen, as if the worst of the epidemic is over. It's not. The worst is yet to come. This budget doesn't recognize that. And it doesn't provide for those sensible activities which could help us reduce the spread, development, and impact of this disease.

There have been 120,000 cases of AIDS in the U.S. in the last eight years, and the health care system in urban areas has been stretched to the breaking point. The Public Health Service estimates that there are one million infected Americans, and that more than half of them have severely compromised immune systems already.

The bill is now coming due, and the Medicaid program will pay a large chunk of it. Last week Kenneth Thorpe, a health economist at the Harvard School of Public Health, told my Subcommittee that AIDS is likely to cost the Medicaid program $2.2 billion next year, and $9 billion over the next 3 years. These costs are concentrated in 8 high-incidence States: New York, California, Florida, Texas, New Jersey, Georgia, Illinois, and Pennsylvania.

Over the past two years, the major research advances in AIDS have been the development of drugs for prophylaxis and early intervention--drugs that will prevent or slow the development of an HIV infection into diseases that require hospitalization. Clearly--both from a humanitarian and a financial vantage point--it is good policy to assure that as many of the one million infected Americans as can benefit from these drugs have access to them. People live longer, healthier, more productive lives. And hospitals have fewer patients and Medicaid fewer costs.

Right now, however, although poor people with full-blown AIDS can qualify for Medicaid assistance, poor people who are infected and have a deteriorating immune system--but who don't yet have full AIDS--cannot. That means that Medicaid will pay when people need expensive inpatient care to <u>treat</u> pneumonia but won't pay when they need drugs to <u>prevent</u> pneumonia. It's a crazy Catch-22 for Medicaid and for the patient. We could prevent sickness, but the only people we help are those who are already sick. Rather than keep people productive, we let them deteriorate. That's stupid---and it's expensive.

In addition to addressing this Catch-22 of early intervention, we must also turn our attention to the hospitals that are caring for AIDS patients. Inner-city hospitals are overflowing now. Without some help, they will be overwhelmed. Public hospitals are on the edge now. Without some help, they will be bankrupt.

Medicaid has become a principal source of financing for AIDS care in these hospitals. The Health Care Financing Administration estimates that 40 percent of all AIDS patients at some point become Medicaid beneficiaries. This comes about for a variety of reasons. Most common is that people with AIDS often lose their jobs and thus their insurance and quickly become poor as they pay their health bills. In addition, the number of women and children with AIDS is growing and the disease is increasingly concentrated among many people who are the poorest of the poor, even before they become sick.

But Medicaid does not begin to pay for the real costs of the epidemic to the hospitals that are treating AIDS patients. While every institution expects the average Medicaid patient to cost it money, AIDS patients cost them a lot of money. According to a 1987 survey, hospitals lost an average of $136 per day under Medicaid on AIDS patients. This is about 5 times the average loss that hospitals reported that year under Medicaid on their average medical/surgical patient.

There are a variety of explanations for why AIDS patients are more expensive: severity of illness, intensity of services, personnel, infection control precautions. But the clear result is that the hospitals which treat high volumes of these patients are facing serious financial problems. If this epidemic continues to spread -- and every indication at this point is that it will -- then many of these hospitals will not survive financially without additional help.

Last week my Subcommittee heard from 3 of these high-volume AIDS hospitals: Jackson Memorial in Miami, Grady Memorial in Atlanta, and New Jersey Children's in Newark. Each of these hospitals has developed care coordination systems with other agencies to keep AIDS patients in the community for as long as possible. But when hospitalization is required, they provide it, and the volumes of such patients are rising.

These are not hospitals that can easily make up losses on Medicaid patients by raising charges to private patients. And these are not hospitals that these communities can afford to lose. While Medicaid may not be able to do much to improve the situation of these hospitals, we can't allow inadequate Medicaid payments to make their problems worse.

Along with a number of Members of this Committee, I have introduced H.R. 4080, the Medicaid AIDS and HIV Amendments. This bill would get early intervention drug services to poor patients while such services are still useful, and would assist those hospitals that are struggling with a very high case loads of AIDS patients.

In addition to these Medicaid improvements, we must also pursue discretionary spending to provide emergency assistance to some areas of the Nation that are hardest hit by the epidemic's past nine years and will be even more stretched to meet the demands of the coming cases. We have depended on the volunteer efforts of local groups for a long time, assuming that they can handle most of the education, out-of-hospital care, and social services needed by people with AIDS. It is becoming clear, however, that many of these voluntary agencies are not able to cope with the scale of the epidemic in the 90's. It is also becoming regrettably clear that many of the individual volunteers are now sick themselves and need government assistance to get the services they so generously provided themselves.

Finally, we must pursue a large-scale program of prevention: Prevention of infection among the uninfected and prevention of disease among those already infected. Such a program involves Federal grants to States and clinics for counseling, testing, diagnostics, and early intervention drugs. With such counseling we can provide uninfected people with the knowledge and reinforcement they need to remain uninfected. Both the Reagan and Bush Administrations have supported such services, but have been unwilling to provide the funds needed to carry them out.

This should not be separated from early intervention services. With such diagnostics and early intervention, we can provide infected people with the medical help they need to slow--or prevent altogether--the deterioration of health and the need for costly hospitalization. All public health and medical groups support such measures.

Clearly there is much more that we must do. But we must make a start. If we do not, our whole public health care system may be flooded with sickness, death, and bad debt, and the communities it serves will be devastated.

Emergency assistance will require perhaps half a billion dollars. Counseling, testing, and early intervention will require half a billion more. And all such expenditures must be built on top of a solid base of continued research, drug development, and prevention activities. The President's budget proposes $1.7 billion for AIDS. My guess is that we need $2.12 billion <u>on top</u> of this amount to fund the needed Medicaid and public health initiatives.

The enormity of the problem is only dawning on most people now, many of whom thought that the epidemic was waning. The President's budget does not begin to meet the needs. This Committee must do so.

PREPARED STATEMENT OF HON. TED WEISS

Madam Chairman, and Task Force members, I thank you for this opportunity to testify on a subject that has occupied my time and attention for many years.

The AIDS epidemic, in its ninth year, is far from over. At the end of January more than 120,000 cases had been reported to the Centers for Disease Control and more than 72,000 had died. CDC estimates that by the end of 1991, a total of 250,000 cases will have been reported. In 1991 alone, there will be 65,000 new cases, and in 1992, 72,000 more will develop AIDS. Last July, eight years into the epidemic, the 100,000th case was reported, and in just eight months from now that number will double.

And yet, in this ninth year of the epidemic, there is no national Executive leadership. As former Surgeon General Koop said last month, a national policy or plan to combat the AIDS epidemic is "almost 10 years overdue."

During the past year, scientists have made stunning developments in preventing the onset of full-blown AIDS in persons who are HIV-infected. The Centers for Disease Control has recommended these treatments for as many as 680,000 of the one million HIV-infected persons in the U.S. These developments offer hope to those who are asymptomatic that they may live longer without AIDS, but they are expensive. Monitoring, testing, and ancillary medical, social, and health care services must accompany therapeutic interventions.

The Assistant Secretary for Health says it is the moral responsibility of the Federal Government to find funds for early intervention treatments. But this has not happened, even though many persons with HIV infection are uninsured and can't pay for early intervention.

Last year the Congress appropriated $30 million for the AIDS Drug Reimbursement Program. These funds paid for drugs -- the main component of early intervention. But this year the President's request for AIDS drugs was zero.

As in the past, it has fallen on the Congress to fill in the Administration's leadership void. For example, Congressman Waxman has introduced a bill which offers a partial solution to the problem of funding early intervention. It would extend Medicaid coverage to those who are impoverished and eligible for early intervention because of their low immune levels. We do not yet know the cost of this bill, but I urge the Task Force to allocate such funds as necessary to cover it.

In addition, I urge the Task Force to allocate significant funding for the AIDS drug reimbursement program, testing, monitoring, medical care, and the other necessary components of early intervention.

The problem of caring for the rapidly increasing numbers of persons who are becoming ill is not limited to AIDS. The AIDS epidemic has focused attention on the crumbling public health care systems in the Nation's cities, both large and small. The resources of hospitals, clinics and other providers of health care, especially for poor and minority patients, are stretched paper thin and they have nowhere else to turn.

Emergency funds are needed to shore up these providers of care. In the past several Congresses I have introduced legislation that would help -- a Public Health Emergency Fund. Today, Senator Kennedy is introducing a bill that also authorizes disaster assistance. I urge this Task Force to recommend sufficient funds to provide emergency relief for communities hardest hit by the epidemic.

Unfortunately, the Bush budget has, in effect, cut, reduced, or failed to increase most AIDS care-related programs in the FY 1991 budget. The Health Resources and Services Administration in HHS requested $186 million for AIDS care and services. But when the President's budget arrived, it contained only $47 million, 25 percent of the agency's request. Let me give you some examples of the cuts:

HRSA requested $45 million for AIDS home health care. The President's budget -- Zero.

HRSA requested $6 million for developing comprehensive AIDS care models. The President's budget -- Zero.

HRSA requested $7.5 million for sub-acute AIDS care. The President's budget -- Zero.

HRSA requested $1.5 million for dental care for AIDS patients. The President's budget -- Zero.

Less than four percent of the funds appropriated for the Public Health Service's AIDS program, from the beginning of the epidemic, has been for direct patient care. The Assistant Secretary for Health told my subcommittee that the first priority of PHS is research on therapies and vaccines, the second is prevention, and "if there are funds left over, they can go into patient care." It is time for the Congress to change this short-sighted balancing act. Persons with HIV and AIDS cannot be cared for with a pittance of left-over funds.

I urge this Task Force to recommend increased support for the care and treatment of HIV-infected persons including early intervention and disaster assistance directed to the hardest hit communities of this Nation.

Once again, the Public Health Service agencies have produced a budget that comes closer to the real needs of the American health care system. All the PHS agencies together have requested that $3.1 billion be appropriated for AIDS research, prevention, and care. Even this amount -- $1.4 billion more than the Bush budget -- is not nearly enough, but this is the minimum that I respectfully urge you to allocate for the continuing struggle against this deadly disease.

PREPARED STATEMENT OF DR. MITCHELL GAIL

Madam Chairman and Members of the Task Force:

I am pleased to be here today to present work done in collaboration with Drs. Philip S. Rosenberg and James J. Goedert of the National Cancer Institute. We wish to acknowledge the help and constructive suggestions of workers at the National Institute for Allergy and Infectious Diseases, the Centers for Disease Control, Johns Hopkins University, and the University of California at Berkeley. As a researcher in medical statistics at the National Cancer Institute, I am here to discuss the scientific aspects of this work.

Since mid 1987, counts of national AIDS incidence have fallen below previous projections in certain groups, such as homosexual and bisexual men, but not in other groups, such as intravenous drug users (see Figures 1 and 2 attached). Indeed, between July, 1987 and December, 1988, 31,436 cases of AIDS were expected among homosexual and bisexual men, whereas 24,687 new cases were reported, based on the 1985 surveillance definition, a decrease of 21 percent. No appreciable decrease was found among intravenous drug users. Moreover, it is well to remember that the total AIDS incidence rate from all exposure groups continues to increase, though at a slower rate than before 1987.

Although other factors such as changes in reporting patterns and changes in behavior that reduced the earlier rate of transmission may have contributed to these favorable incidence trends, we believe that the decreases seen have resulted mainly from the increasing use of zidovudine ("AZT") since March, 1987 and possibly from other treatments that can retard the onset of AIDS-defining pneumonia. Support for this hypothesis comes from data on the extent of treatments used in the San Francisco Men's Health Study and other cohorts and

from data on the number of homosexual men in the United States with severe immunodeficiency who received AZT in 1987 before developing AIDS. My colleagues and I believe we have demonstrated that treatment of a few thousand severely immunodeficient individuals who did not yet have AIDS was sufficient to account for most of the lowering of national AIDS incidence rates among homosexual and bisexual men.

Although these favorable incidence trends mark an important advance in the treatment of persons who are infected with the human immunodeficiency virus (HIV) and who have severe immunodeficiency, these favorable trends in incidence are not grounds for complacency. We believe that the abrupt improvements in incidence beginning in 1987 primarily reflect the impact of new treatments and do not imply that fewer persons are infected with HIV. Indeed, our statistical models and completely independent survey data from the Centers for Disease Control indicate that about one million persons are infected with HIV in the United States. Moreover, new infections continue to occur at an estimated rate of over 100 per day.

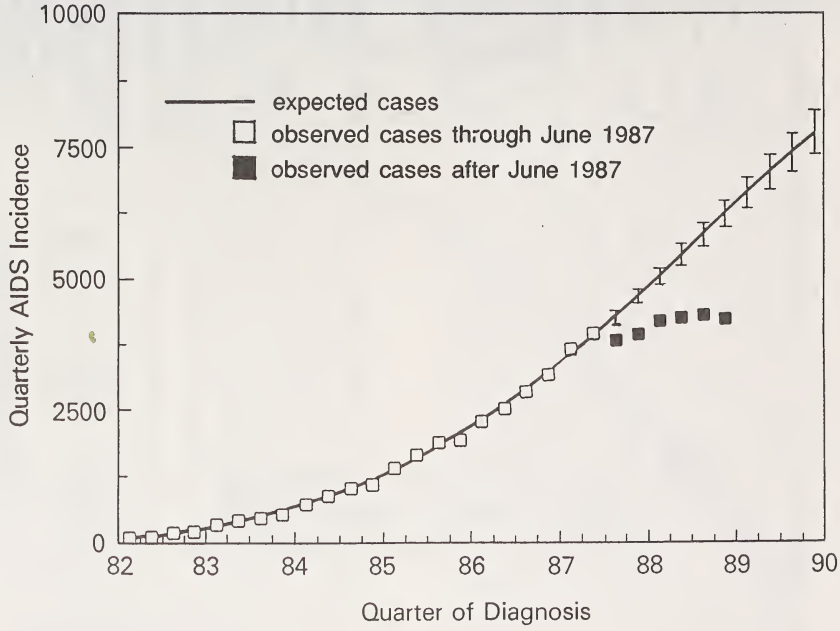
Several implications follow from these facts.

1. Many of these one million infected individuals will eventually progress to AIDS, despite treatment, unless a cure is found. Thus, current incidence trends should not be misconstrued as suggesting that the AIDS epidemic is on the decline. For the country as a whole, AIDS incidence continues its upward course.
2. With so many infected, the potential for further spread of HIV infection remains great. Prevention efforts should remain a primary goal.

3. Populations without adequate access to zidovudine and other treatments should be identified, and access to treatment, especially for those with severe immunodeficiency, should remain a priority.
4. Further research is needed to validate our findings and to quantitate the extent to which other factors may be contributing to current trends in AIDS incidence. Possible factors include changes in AIDS reporting patterns as well as behavioral changes that have reduced the transmission rate of HIV infection in some exposure groups.
5. Finally, research is needed to strengthen our tools for controlling the impact of HIV infection, including strategies to prevent the further spread of infection, especially among intravenous drug users, to develop improved treatments, and to provide medical access to treatments of proven efficacy.

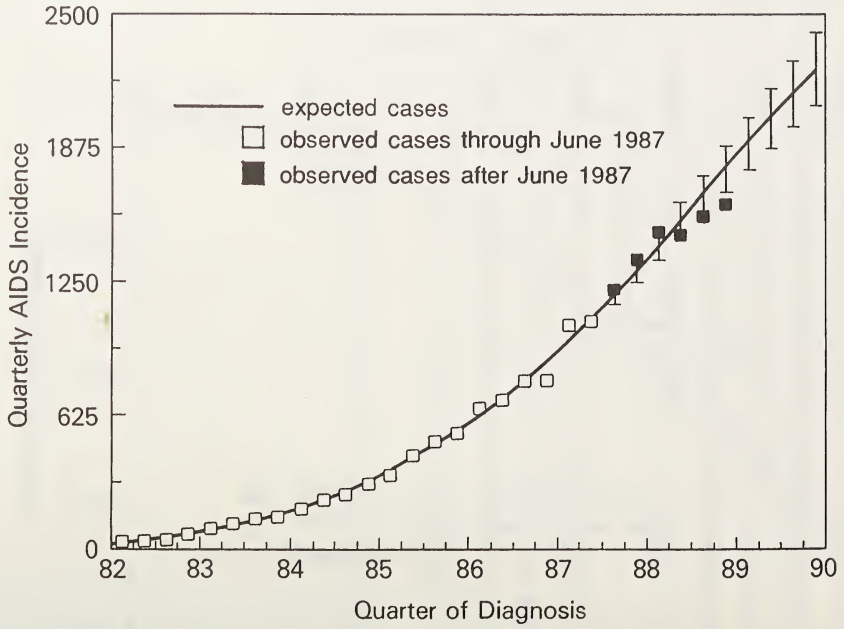
Thank you for his opportunity to speak and to clarify questions you may have about the data presented here.

Figure 1. AIDS (1985 Definition) Incidence Among Homosexual and Bisexual Men in the United States*



* Adapted from Figure 1 in Gail, M.H., Rosenberg, P.S. and Goedert, J.J.: Therapy may explain recent deficits in AIDS incidence. *J. AIDS* 1990 (in press). Vertical bars indicate 95% confidence intervals on the expected counts.

Figure 2. AIDS (1985 Definition) Incidence Among Intravenous Drug Users in the United States*



*Adapted from Figure 3 in Gail, M.H., Rosenberg, P.S. and Goedert, J.J.: Therapy may explain recent deficits in AIDS incidence. *J. AIDS* 1990 (in press). Vertical bars indicate 95% confidence intervals on the expected counts.

PREPARED STATEMENT OF PETER S. ARNO

During the past year, major advances in the treatment of HIV disease have been made. In August 1989, the largest clinical trial ever conducted among persons with HIV disease was halted when low dosage AZT was found effective in slowing the progression from HIV infection to AIDS.[1] Based on the findings from this study the Food and Drug Administration (FDA), just a few days ago (March 2, 1990), approved a new labelling change for the use of AZT among HIV-infected individuals prior to an AIDS diagnosis.[2] The National Institutes of Health held a consensus conference this past weekend on AZT therapy for early HIV infection and endorsed the FDA labelling change. The NIH panel "strongly recommended that AZT therapy be initiated for asymptomatic HIV positive individuals with CD4 lymphocyte counts below 500."[3]

Progress has also been achieved at preventing and treating opportunistic infections, particlularly *Pneumocystis Carinii* pneumonia (PCP), the most common presenting infection among patients with HIV disease. Since June of 1989, the Centers for Disease Control have recommended CD4 cell monitoring for all individuals infected with HIV, followed by pneumocystis prophylaxis for all those with CD4 cell counts below 200.[4] Recent findings from the Multicenter AIDS Cohort Study (known as the MAC study) further corroroborate these CDC recommendations.[5] Thus, specific antiviral therapy and chemoprophylaxis for some opportunistic infections represent major clinical advances in the management of HIV infection. These advances may indeed account for some of the recent improvements we have seen in survival rates among persons with HIV disease[6,7] as well as lower than expected incident cases of AIDS.[8]

We have also made important strides in our understanding of the markers of disease progression which can help tell us when in the course of HIV disease to begin preventive treatment. Ho, Coombs and their colleagues have demonstrated that there is continuous viral replication which is well correlated with disease progression.[9,10] This implies that effective, nontoxic drugs that limit HIV replication may prolong the chronic phase of infection and prevent the crisis or symptomatic phase of this disease. It also suggests that markers such as the magnitude of plasma viremia may may be an accurate indication of the staging of illness which should prove

useful not only in measuring the efficacy of ongoing treatments but may also provide a scientifically rigorous basis for smaller, quicker, and cheaper running of clinical trials for new therapeutic regimens.

These developments add further weight to the growing body of evidence that suggests that persons in later stages of disease bear a greater viral burden and are therefore more infectious. This underscores the possibility that therapies which reduce viral replication may also reduce viral transmission and stem the spread of new HIV infections.

Understanding the meaning of an effective early intervention strategy requires us to shift our thinking of this epidemic by an order of magnitude.[11] From the point of view of the health care system we can no longer think only of the 50,000 persons living with AIDS in this country who require a wide range of medical and social services. We must now consider the other 800,000 to one million persons who are HIV-infected who require a new set of health and social services that are not even fully conceptualized let alone available.

The organizational and financial demands of an equitably distributed early intervention program are considerable. These include the provision and coordination of ambulatory care services for large numbers of new patients. Important questions regarding the sites of health care delivery, the provision of trained personnel, and the primary care approach to HIV disease need to be addressed. The ability of our health care system to fulfill this task – by providing adequate HIV testing, counseling, laboratory monitoring, medications, and over-all primary health care – is currently inadequate. Moreover, these centers can expect an increase in the number of clients, since many recipients of HIV-related services will be new patients who have not previously needed close ambulatory attention. These difficulties are compounded because a growing number of persons with HIV infection are intravenous drug users, their sexual partners, and families who live in neighborhoods that are the most medically underserved and understaffed.

To accomplish these goals requires nothing short of revamping the ambulatory care network in our inner cities, such as it is. To relieve the

crisis in the hospital sector and to provide care to those that need it will require major new resources and new funding streams for primary care.

I do not believe we need a seperate new system of HIV centers but rather we need to integrate HIV testing, counseling, monitoring and treatment into a new more humane and accesible system of overall primary health care.

Expanding categorical eligibility under the Medicaid program as suggested by Congressman Waxman in H.R. 4080 will go a long way to improving access to primary care and to life prolonging medications and is certainly a step in the right direction. However, we should be mindful of the system we are creating access to. Why is it that for a routine physician office visit for a new patient in New York City, Medicare pays $81, Blue Cross pays $84 and Medicaid pays $12, or for a bronchoscopy: Medicare pays $750, Blue Cross pays $775, and Medicaid pays $60? Correcting these differentials is long overdue and absolutely necessary if we want to provide a semblence of equity in access to care for all our citizens.

To illustrate the problem another way I would like to read to you a short anecdote related to the New York State Assembly Committee on Health by David Barr from the Lambda Legal Defense and Education Fund in a recent hearing on primary care and HIV:

After describing how his private primary care physician played an essential role in his treatment plan he described this recent incident of someone less fortunate:

> "The social worker of a Latina women in the Bronx who had recently tested HIV positive called to tell me about her client. The women had tested positive and was fortunate enough to know that she should follow up with a T-Cell test. A Medicaid recipient, she went to the clinic at the public hospital in her neighborhood. A blood test was done. Every two weeks she returned to the hospital and was told that her test results had not been received. She speaks little English. Finally, after waiting ten weeks, she returned to the hospital with a social worker who

> speaks Spanish. They waited for three hours only to have the doctor tell her that again her test results were not available and that she should return in two weeks. The doctor then said that since she was HIV positive, she should start taking 1500 mg of AZT every day, wrote a prescription and left."[12]

Is this the type of bifurcated early intervention program we are building: one for the well educated and well insured and another for the poor who must rely upon government-sponsored programs?

I do not believe that HIV disease is a series of local problems which can be solved by new policies at the city or state levels alone. What has been desperately lacking during the past nine years of this epidemic is national leadership and a federal AIDS program. The Kennedy bill to provide emergency relief to the nation's hardest hit regions provides a ray of hope to our beleaguered cities, their health care systems, and to the hundreds of thousands of HIV-infected persons who are our neighbors, families, friends and loved ones. In addition to an infusion of federal resources, the enactment and enforcement of strong federal antidiscrimination statutes would ease the transition to wider acceptance of voluntary testing, monitoring and treatment programs.

What is all this going to cost and how can it be financed? Great uncertainty surrounds most of the parameters one needs to estimate to determine the costs for an early intervention program that is national in scope. These include, for example, the number of seropositive individuals, the number of persons who come forward for antibody testing and counseling, many of whom may not be HIV-infected, the number of those who choose to be treated and the most appropriate sites to deliver these services. One option to help elucidate appropriate and cost-effective treatment models would be to incorporate credible evaluation components as part of a national strategy to begin early intervention programs across the country. These could be funded by the Agency for Health Policy Research, the Health Resources and Services Administration or the Centers for Disease Control.

Taking into account the latest FDA and NIH recommendations, I have refined our model[8] to estimate the demand and costs for the first year of a national early intervention program if it were in fact begun in earnest. There are three major components to such a program (see tables): I. Testing and counseling ($35 million); II. Monitoring the seropositive population ($211 million); and III. Treatment ($951 million). All told, this program would cost approximately $1.2 billion during the first year, which represents less than one half of one percent of total national health care spending. Moreover, these costs would not be born solely by the federal government. Along with a central role of the federal government, costs would be distributed to states and localities through Medicaid and other public health programs and to the private sector through the health insurance industry.

The vail of medical uncertainty regarding early intervention has been lifted by the recent FDA and NIH recommendations. The time for equivocation is over. We must act now.

****

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Annual Early Intervention Monitoring and Treatment Model

Table 1: Monitoring

Initial Visit (comprehensive exam)	$285	-	$319
Bi-annual Monitoring (CD4 cell count; CBC)			
2 visits/yr @ $100-$126/visit	200	-	252
	$485	-	$571
Midrange Estimate	**$528**		

Table 2: Treatment

Ambulatory visits			
8 visits/yr @ $66- $75/visit	528	-	600
Pharmaceutical expenditures			
Anti-retroviral treatment			
AZT @ 500 mg/day	2,700	-	2,700
PCP prophylaxis			
aerosolized pentamidine	1,080	-	1,500
Other drugs			
(eg., acyclovir, ketoconezole and clotrimazole)	540	-	540
Subtotal	$4,848	-	$5,340
Midrange Estimate	**$5,094**		

Table 3:
ESTIMATED DEMAND AND COSTS FOR FIRST YEAR: NATIONAL EARLY INTERVENTION TREATMENT AND MONITORING PROGRAM

Estimated No. of Persons	Cost/ Service$	Costs in Millions of dollars
All Seropositives 800,000		
Testing and Counseling 500,000[1]	70	35
Monitoring 400,000[2]	528	211
In Treatment 186,667[3,4]	5,094	951
	TOTAL	**$1.2 BILLION**

[1] Estimate includes antibody testing and pre-test and post-test counseling. A significant proportion of these individuals will be seronegative and require no further monitoring or treatment.

[2] Assumes half of all seropositives will begin monitoring programs.

[3] Assumes antiviral treatment and PCP prophylaxis for all persons with CD4 cell count below 200 plus 33.33% with CD4 cell count between 200 and 500. Only one third of the latter eligible group is estimated to begin treatment because of the large number of infected persons who may not come forward for testing or who refuse treatment.

[4] It is further assumed that 10% of the population < 200 CD4
40% of the population = 200-500 CD4
50% of the population > 500 CD4

PREPARED STATEMENT OF TIMOTHY J. SWEENEY

My name is Timothy J. Sweeney. I am the Deputy Executive Director for Policy at the Gay Men's Health Crisis (GMHC), based in New York City. GMHC is the nation's oldest and largest community-based AIDS service, education and advocacy organization. Since our beginning in 1981, GMHC has directly served over 8500 people with AIDS or ARC. We have answered 300,000 calls for information on our Hotline. We have distributed 3,000,000 pieces of life saving information. We have trained thousands of health and mental health providers. The vast majority of our work has been done by volunteers. We currently have 1700 volunteers giving over 10,000 hours of time every month - lawyers, social workers, therapists, cooks, office workers and nurses.

I speak to you today as a representative of the thousands of community-based AIDS organizations providing psycho-social support, counseling, case management, food programs and legal and financial advocacy to the HIV-ill and their families, and prevention education and medical information to the general public and targeted populations. I am here to tell you that while we fully believe in a private-public partnership, in the nation's war against AIDS, the voluntary sector has been carrying a

disproportionate burden in that war. For instance, at GMHC, over 75% of our budget is privately raised. We are falling farther and farther behind. We are losing the battle. Our caseloads are increasing at a rate far outpacing our funding. In New York City the caseload is expected to increase from the 22,000 AIDS cases reported at the end of 1989 to 33,000 by the end of this year - an increase of 50%. In San Francisco, the caseload at the end of 1989 was 7,700 and it is expected to climb to almost 12,000 people with AIDS within the next two years - also a 50% increase. While today GMHC has 2800 clients, a year from now we will have 4,000. We truly don't know how we are going to meet their needs.

Community-based organizations are the nation's frontline troops in the war against AIDS. We have the credibility and the expertise to take messages on sexuality and drug use to people most at risk. However, we do not have the ammunition to win. We need large scale federal assistance in the form of emergency relief. The programs at HRSA need to be expanded immediately. The Public Health Service must recognize that it shares in the care responsibilities. This will bring to all local efforts immediate financial assistance, but especially those in the hardest hit cities. HIV-positive individuals, our families and community-based organizations will be active and vigilant participants in local planning efforts to determine program priorities for funding.

With increasingly helpful therapeutic developments, we are reaching many more individuals and families who want services. But the sad fact is that while we have begun to see the results of our billion dollar investment in biomedical research, those therapies are out of the financial reach of the vast majority of those who need them. In addition, as AIDS education and outreach expands, individuals and families at risk are stepping forward to be tested. For those who are finding out they are positive, we begin the intake and referral process. In August and September of this last year, GMHC's Hotline was receiving 38% and 40% increases in calls. Most of those callers had heard about promising developments and wanted information on testing, AZT and where to find medical care. There are few places we can send them. The frustrating and angering truth is that many of these callers do not have insurance and can not afford a private doctor. Our local community health clinic was so overwhelmed by requests for help that they closed their waiting list for two months. They are caring for 1400 HIV-ill individuals with just two doctors. Our local self-help counseling group for HIV-positive individuals, Body Positive, has a counseling group made up of male drug users who want to get into treatment but are on waiting lists. Thousands of people in New York City are on waiting lists for residential drug treatment programs. They must wait weeks or months. For those who do get ill and enter the hospital system, other barriers confront them. GMHC's Ombudsman office constantly investigates complaints of people with AIDS waiting days in emergency rooms for a hospital

bed. Both in the public and voluntary systems, critically ill people can wait as long as eight and ten days. This last December, two of our clients died in the emergency room in a voluntary hospital while waiting for a bed. One waited eight days; the other waited nine days.

And we know in New York City we are at the tip of the iceberg. According to the New York City Citizen's Commission on AIDS, up to 225,000 New Yorkers are HIV positive. According to the New York City Department of Health, 117,000 New Yorkers who are HIV positive have a T-cell count below 500. With the latest recommendations from the Secretary of Health, those 117,000 individuals should be receiving medical care in an early intervention program. The Secretary's recommendations mean that the number of people who should be receiving services has increased tenfold. We know what we need to care for these individuals. The HSA New York City Task Force on AIDS says we need the following, for just these limited categories:

Category	1993 Need
Acute Beds	4,020
Housing Units	2,640
Health Related Facility Beds	590
Skilled Nursing Facility Beds	630
Home Care Average Daily Enrollment	3,450
Physician Visits	1,003,620

The cumulative costs for providing such services through 1993 were also projected:

Category	Costs
Acute Beds	$4,409,000,000
Housing Units	233,000,000
Health Related Facility Beds	130,000,000
Skilled Nursing Facility Beds	235,000,000
Home Care Average Daily Enrollment	634,000,000
Physician Visits	496,000,000

Increased federal aid will help us stave off disaster in New York City. The New York Times was not exaggerating when it said New York is in danger of becoming the new Calcutta. As I sit before you today in Washington, fifteen more individuals -- men, women and children -- were diagnosed with AIDS in New York City. Four more people with AIDS came to GMHC for help today. We must have a new and renewed national effort to provide leadership and resources to win our war against AIDS.

PREPARED STATEMENT OF DR. JUNE E. OSBORN

Good afternoon, Congresswoman Boxer and members of the Committee. I am Dr. June Osborn, Dean of the School of Public Health at the University of Michigan and Chairman of the National Commission on AIDS. I want to tell you about some experiences the Commissioners have had recently that intensify our sense of urgency about meeting health care needs of people living with HIV and AIDS. All these impressions lead to the same conclusion: that over the past decade the U. S. has suffered the accelerating emergence of a human disaster that is unequally distributed across the country, that dwarfs in scale the physical disasters of recent times, and that begs for an urgent federal response such as that embodied in "Impact Aid".

Since the beginning of January, the Commission has visited some of the areas most severely affected by the first decade of AIDS, including southern California, New York and New Jersey. Furthermore, as chairman, I joined Mayor Agnos of San Francisco in January to help make public the product of a year's work by his AIDS Task Force -- an event I will mention at the close of my remarks.

Let me share with you some impressions of the New York-New Jersey visit of last week, since they are indelibly etched in my mind. [Parenthetically, a number of the Commissioners have told me that they, too, have found it impossible to shake the effects of what we saw when we visited there, and have barely been able to sleep since our visits with the homeless of New York.]

The anguish we witnessed -- the destitution, the unthinkable daily jeopardy of persons who lack homes and food and health care, whose families have been decimated by poverty and chemical dependency, and whose lives are now under threat from HIV and AIDS -- all those abstract components of tragedy took human shape in the narratives of personal experience, and were made all the more real to us by the poignant pleas for understanding by the homeless people we talked with. The brave advocates and outreach workers who facilitated our meetings left me in awe of the courage they display just in returning, day after day, to a battle where they have no ammunition and, indeed, no battlefield on which to stand.

Images of our visit to the Fort Washington shelter are burned as indelibly on my retinae as if I had stared into the cruel winter sun. Nine hundred thirty-three men sleep there nightly (a slightly different group each night, depending on who is lucky enough to line up in time for a cot). The very great likelihood is that a majority of those huddled there -- when we visited on the coldest night of the year -- were infected with the human immunodeficiency virus. As a physician, I found that almost beyond contemplation! That should definitely be against medical advice!!

But even in that unthinkable place, humanity shone through from what seemed the least likely of directions. A couple of destitute homeless men, showing their positive tuberculin skin tests to the Commissioners, voiced their concern that -- and I

quote -- "people who are extra-susceptible to infections should never be sleeping in a place like this!"

Fort Washington was not the only horror. During our travels we heard about families not only broken but kept asunder by rigid visitation rules for addicted mothers -- even those under treatment. We heard from people who had at least staked out a specific shelter site, who were suddenly being shuttled from one remote cot to another, coincident with authorities learning of their HIV-positive status. Outreach workers told us of the extraordinarily brisk response of addicts to take up the hope offered by new drug treatment slots -- and of the anxiety of the conscientious health professionals at drug treatment clinics about how they would cope when the one-year-only funding wore out and freshly recruited addicts in treatment could no longer be accommodated. We heard tales of health care denied unless it required acute hospitalization, and we heard desperate pleas in New Jersey that something be done to ensure that all hospitals participate equally in provision of under-reimbursed AIDS care, rather than continue the grossly disproportinate distribution resulting from the subtle "patient dumping" now practiced.

All this would have been troubling enough; but one could not escape the nagging awareness that if we are so far behind now, what will we do as the case numbers double within the next two years? and how can we be urging that people come forward for HIV testing using the lure of early interventive evaluation and treatment, when health systems are collapsing with one-tenth their number and when discrimination seems a far more likely result than compassionate care? The mere word "disaster" is not strong enough to describe what we have seen, for in a very real sense, the "human" has been leached from "human services" in a way that should shame us all!

I am a member, also, of the Global Commission on AIDS of the World Health Organization, and in November we met in central Africa, undertaking similar visits in an effort to appreciate the impact of the HIV epidemic there. I came back much shaken, for in Kinshasa I had seen hospitals where the beds were lined up 30 in a row with only enough space between them for family to stand and tend to their loved ones themselves since there were no nurses; and half those beds were filled with people with AIDS. There was no pharmacy, no food service, no laundry; and the doctors had not been paid for several weeks -- but at least there were families, and they were doing their best. I thought, after that, that I had seen it all, but after last week I realized that even central Africa paled in comparison to some of what is happening in the shadow of the Statue of Liberty! We are seeing drugs and poverty and hopelessness -- and now HIV and AIDS -- threaten to complete the investiture of an "underclass" in our once-proudly classless land of opportunity.

By inattention we have let our cities slide into a silent social disaster. There are more homeless in New York in 1990 than there were at the depths of the Great Depression, and now their

ranks are being swollen further by AIDS. The despairing people in New York, in Jersey City and Los Angeles, in Newark and San Diego must find it harsh and bitter to hear about the wonderful biomedical research progress against HIV, about increasingly effective treatment for AIDS, and about the promise of early intervention -- when they cannot even get access to primary care! Even the emergency rooms on which they depend in times of crisis are closing their doors, as public hospitals teeter on the brink of collapse. It is indeed a disaster! There were no carefully engineered steel rods in the health care edifice that was so casually erected over the past several decades, and the crumbling has begun in earnest!

It is often said these days that AIDS is "just one disease" -- that we have focussed enough resources on it and should now move on to other diseases and issues. I could not disagree more strongly! In a very important sense, AIDS is a metaphor -- the only really new things about the HIV epidemic are the virus itself and the pressure of burgeoning numbers of young adults needing sustained care. All the rest of the problems we face are old ones that we have ignored or patched or minimized beyond all common sense.

There is a ghastly public complaisancy in this country right now about the AIDS epidemic, stemming (I fear) from the sense that it is happening to "others." Soon we will get over that, for we will all know someone caught in the sad web of blighted lives and premature death. We might have the help of that universal awareness even now, were not so many people grieving in secret for fear of discrimination or perceived disgrace. We have had over 120,000 cumulative cases of AIDS in America, and over 70,000 have died. Those awful numbers will double and double again during this decade, even if we could stop further virus spread tomorrow! We must recognize this for the disaster it is and respond humanely. And we must, at the same time that we take urgent action, proceed to make amends for the heartless omissions of past decades and plan carefully for the compassionate care of all our citizens. If we do so thoughtfully, our efforts will have benefits far beyond the range of the HIV epidemic.

I mentioned at the beginning that I had been to San Francisco in January, and it was a gleam of light in this dark time. There is no question there about whether AIDS is a disaster. And the Task Force report I helped to "launch" gave inspiring testimony to what a community can do when it pulls together to face the problems squarely, uniting business and health care and religion and minority and community activist groups with government in a common and coordinated response. There is no doubt that the San Francisco plan will be demanding -- in fact, I strongly suspect that emergency federal relief through Impact Aid may constitute the marginal difference between success and failure. But the example of a united front against this awful disease reminds me again of the power of family -- of just how powerful we can be in the face of disaster when we remember that we are all one human family!

Note: The text of a full address delivered on December 1, 1990 to the Harvard AIDS Institute by Dr. Osborn at their World AIDS Day observance was introduced by Congressman Louis Stokes into the Congressional Record of January 31, 1990 (see pages E141-144).

PREPARED STATEMENT OF JEAN F. McGUIRE

Chairwoman Boxer and Task Force Members, I am Jean McGuire, Executive Director of the AIDS Action Council, the national public policy arm of AIDS service organizations around the country. I am here today in my capacity as chair of the National Organizations Responding to AIDS (NORA), a coalition of over 150 national agencies working for the development of a comprehensive national strategy for the epidemic.

I certainly cannot paint for you a more graphic picture of how desperate the situation on the frontlines is today than you have already heard from the other witnesses. Hospitals and poverty health settings are crumbling under the weight of this disease, community based organizations are turning people away, early intervention is not an option for a significant number of those currently infected, and meaningful prevention efforts have yet to begin for many of those most at risk.

While epidemiological information may suggest that slightly fewer than the numbers originally anticipated are currently infected, and that, because of early interventions for some, AIDS caseloads are climbing less rapidly, there is no information that should be misconstrued to suggest that the worst is over or that the impact is lessening. We only wish that were true. And we fear that the complacency that is being engendered by careless discussions about the implications of projections will lessen our nation's commitment to a meaningful treatment options and an expanded prevention agenda.

The great needs you have heard discussed today require aggressive plans for action and substantial allocations of resources. Neither is available in the AIDS budget that was presented to you by the Administration. However, responsive elements of a comprehensive plan are contained both in the disaster relief proposal that was brought over to you today by Senator Kennedy and his colleagues and in the early intervention initiative that has been put forward by Mr. Waxman. In addition to these both, we need the type of national prevention strategy advocated by Ms. St.Cyr-Delpe and others during the course of the hearing.

To be effective, these proposals must be well funded. They are not cheap. However, to ignore the urgency of the need will be to bargain for considerably greater costs, and more human loss, in the future.

Within the next two weeks, the NORA coalition will present to Congress our budget and appropriations recommendations for FY1991. We will be calling for more than a billion dollars over the President's recommended funding levels. (I would remind the Task Force that the President's FY1991 AIDS funding proposals, while duplicitous in their presentation because of the inclusion of entitlement and other expenditures in excess of the PHS allocations, also cut well under what his own executive agency recommended for discretionary spending levels for the fiscal year we are currently in.)

We feel strongly that there are two things that dictate such a considerable infusion of resources. First is the desperate situation in which the hardest hit jurisdictions currently find themselves. We cannot let the health and social service structures that have been the backbone of our nation's response to this epidemic crumble - what will happen then? As a nation, we have found the capacity, usually quite easily, to respond to earthquakes, hurricanes, and other disasters... why should the disaster this disease has created be any less compelling?

As you undertake your fiscal deliberations, we urge you to assume the provisions contained within the Comprehensive AIDS Resources Emergency Act introduced in the Senate today. I have attached to my testimony the still expanding list of those NORA organizations already supporting this measure.

The second major factor that should urge us to quick and meaningful action is the discovery over the course of the last year that early intervention can interrupt the progression of this disease, buying precious time for those who are currently infected. Although you have heard it elsewhere today, it bears repeating to note that, according to CDC's own estimates, over half of those who are currently infected have sufficiently compromised immune systems that they should now be in prophylactic treatment of some kind. It is unconscionable to think that the nation's hard and costly won HIV research discoveries may be meaningless to most of those affected because access to treatment remains an illusion.

Over 35 of the NORA organizations already have endorsed Congressman Waxman's HIV and AIDS Medicaid Amendments Act of 1990 (see attached) and feel strongly that its provisions will greatly enhance access to early interventions for individuals who are poor. The proposed categorical eligibility for asymptomatic individuals is an aggressive and appropriate response to an overwhelming access dilemma.

We understand that Congressman Waxman will also be proposing an additional program which will allow for prevention counseling, testing, and early intervention services to be located in settings where health related services are provided to those who are poor but may not necessarily be covered by Medicaid. This proposal is an important component in a comprehensive early intervention agenda.

Finally, we will be looking to the Congress to both recommit itself to the ongoing search for treatments and to intensify national prevention efforts. Because of your efforts so far, we have been able to build the necessary infrastructure to support the aggressive HIV research activities which have yielded the promise of early interventions. However, there are insufficient funds in the proposed budget to sufficiently pursue alternative treatments for opportunistic infections which offer perhaps the greatest hope for truly making AIDS a chronic and manageable disease. We are also concerned that women, minorities and children continue to be seriously underrepresented in the clinical trials and that the need

for more extensive pediatric AIDS research continues to be underfunded.

The prevention activities that have been undertaken so far have produced results in certain targeted communities. But there are many communities where the work has yet to begin. Moreover, we must rethink our interventions and understand that the behavior changes we are seeking are difficult to acquire and then to sustain - consequently, prevention must be seen as an ongoing effort.

A national prevention strategy requires leadership we have yet to see from anywhere - the agencies, the president, or the Congress. The impetus for a national commitment to prevention comes from the streets where the devastation is happening. But it will be meaningless without visible leadership here in Washington.

NORA will submit a comprehensive federal AIDS budget proposal to you within the next two weeks. We hope it will help guide the Task Force in its deliberations. Thank you.

Attachments.

National Organizations Responding to AIDS

For Immediate Release
March 5, 1990

For more information: Tom Sheridan, AIDS Action Council (202)293-2886.

Over Fifty National Organizations Call for AIDS Care Response

WASHINGTON-- This morning Senator Edward Kennedy introduced a bill to provide $500 million in federal assistance to states and cities for AIDS care. Calling today's action by Senators Kennedy and Hatch and (20) other co-sponsors "the most urgently needed and responsive AIDS initiative yet" more than 50 national organizations called on Congress to press for expeditious passage. The coalition of professional, service and community organizations known as the National Organizations Responding to AIDS (NORA) joined the Senate co-sponsors, Elizabeth Taylor, Mayor David Dinkins, and The National AIDS Commission in a Capitol Hill press conference this morning.

The bill formally called the "Comprehensive AIDS Resources Emergency Act of 1990" (CARE), calls for $500 million in federal assistance to all states to assist in planning and coordinating services for people with HIV. A major component of the legislation provides for "disaster relief" for the thirteen cities hardest hit by the epidemic. "The nation's ability to respond with generosity and support to disasters such as Hurricane Hugo and the San Francisco earthquake provides the spirit upon which this bill is based" said Jean McGuire, chair of the NORA coalition. With more Americans lost to AIDS than any natural disaster or war in the last 30 years "this bill is a great example of sound legislation; built upon compelling need, responsive in an unprecedented crisis and compassionate in an appropriate and cost-effective manner" continued McGuire.

Calling the nation's ability to respond to the care needs of children, women, adolescents and men with AIDS and HIV infection as "burdened to the point of collapse", Donna Richardson of the American Nurses Association applauded the bill's ability to "empower communities to build upon existing systems and unite communities around the common decency of care". To date the federal response to AIDS has primarily focused on the prevention, education and research issues but not on the critical issue of assistance to people in accessing necessary care.

"This nation's billion dollar investment in AIDS research will only be profitable if access to the treatments is assured to people with HIV infection at the earliest opportunity" said Mike Merdian, of the National Association of People with AIDS. This bill gives both the necessary resources and the local flexibility to allow communities to begin the development of these service systems.

Noting that the President has recently sent $500 million to Panama for assistance and the same sum to US boarder cities to assist in the interdiction of illegal drugs, McGuire stated "we are hopeful that the President will endorse this bill as an equal partner in the priorities of our nation".

The National Organizations Responding to AIDS (NORA) is comprised of over 140

a coalition convened by
AIDS ACTION COUNCIL
2033 M Street, N.W. • Suite 801 • Washington, D.C. 20036
(202) 293-2886 • FAX (202) 296-1292

professional, religious, and AIDS service groups. The coalition was founded in 1987 and is currently the major political voice on AIDS and HIV on Capitol Hill.

AIDS Action Council
AIDS National Interfaith Network
American Anthropological Association's Task Force on AIDS
American Association for Counseling and Development
American Association for Marriage end Family Therapy
American Association of University Affiliated Programs for Persons with Developmental Disabilities
American College Health Association
American Federation of State County and Municipal Employees
American Foundation for AIDS Research
American Home Economics Association
American Medical Student ASsociation
American Nurses' Association
American Psychological Association
American Public Health Association
Association of Schools of Public Health
Catholic Health Association of the United States
Center for Population Options
Chronic Fatigue Syndrome Information Institute Inc.
Citizens Commission on AIDS
City of Chicago
City of New York
City of Philadelphia
Coalition for the Homeless
Committee for Children
Consortium of Social Science Associations
Federation of Parents and Friends of Lesbians and Gays
Human Rights Campaign Fund
Infectious Diseases Society of America
Legal Action Center
National AIDS Network
National Assembly of State Arts Agencies
National Association of State Alcohol and Drug Abuse Directors
National Association for Home Care
National Association of Community Health Centers Inc.
National Association of Counties
National Association of People with AIDS
National Association of Protection and Advocacy Systems
National Association of Public Hospitals
National Association of Social Workers
National Council on Alcoholism and Drug Dependence
National Council on La Raza
National Gay and Lesbian Task Force
National Hemophilia Foundation
National Hospice Organization
National Minority AIDS Council
National Puerto Rican Coalition
National Urban Coalition
Rainbow Lobby
Service Employees International Union
Sex Information and Education Council of the U.S.
The United States Conference of Mayors
United States Conference of Local Health Officers
UJA -- Jewish Federation of New York

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National Organizations Responding to AIDS

FOR IMMEDIATE RELEASE
February 27, 1990

Contact: Jean McGuire (202) 293-2886
Tom Sheridan

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37 NATIONAL ORGANIZATIONS ENDORSE WAXMAN INITIATIVE

Washington, DC - Thirty seven member agencies of the National Organizations Responding to AIDS (NORA) today endorsed Congressman Henry Waxman's (D-CA) Medicaid AIDS and HIV Amendments Act of 1990.

Calling it "the most serious AIDS health care initiative yet," Jean McGuire, Executive Director of the AIDS Action Council and chair of NORA committed the coalition's support to passage of the bill this year. "This bill is the type of serious response to the AIDS epidemic we have been waiting for from Washington" Mc Guireconcluded.

The Waxman proposal, cosponsored by Representative James Scheuer (D-NY), includes four Medicaid reimbursement improvements targeted both to increase access to early interventions as well as to improve the provision of care to those who are already sick. Through a disproportionate share provision, hospitals serving the largest numbers of AIDS patients would receive enhanced reimbursements. Through the pediatric proposal, states would have more flexibility in developing and paying for out of hospital care. Chris Burch of National Association of Public Hospitals noted, "The proposed relief can't come soon enough."

In an extension of already existing authority, state Medicaid programs would be allowed to use their matching federal dollars to pay for COBRA insurance premium extensions, allowing for a better public-private sharing of the costs of care.

Donna Richardson, American Nurses Association, called the new categorical eligibility provisions for asymptomatic individuals, "the most far-reaching of the proposed improvements, and a direct response to the promise of early interventions for thousands of Americans." These provisions will allow people with HIV, who are not yet necessarily sick, to get access through Medicaid to pharmaceuticals and certain types of ambulatory care. Sandy Harding, National Association of Social Workers, particularly commended the recommended case management services for assuring the availability adequate health and social service planning.

Mike Merdian, Executive Director of the National Association of People with AIDS, noted that the Waxman-Scheuer package was "the beginning of a truly comprehensive federal approach to HIV disease."

AIDS Action Council
AIDS National Interfaith Network
American Academy of Pediatrics
American Anthropological Association's Task Force on AIDS
American Association for Counseling and Development

-more-

American Federation of State County and Municipal Employees
American Home Economics Association
American Nurses' Association
Americans for Democratic Action
Center for Women's Policy Studies
Chronic Fatigue Syndrome Information Institute Inc.
Citizens Commission on AIDS
Committee for Children
Federation of Parents and Friends of Lesbians and Gays
Hospice Association of America
Human Rights Campaign Fund
Infectious Diseases Society of America
Legal Action Center
National AIDS Network
National Association for Home Care
National Association of Community Health Centers Inc.
National Association of People with AIDS
National Association of Public Hospitals
National Association of Social Workers
National Council on La Raza
National Gay and Lesbian Task Force
National Hemophilia Foundation
National Hospice Organization
National Mental Health Association
National Network of Runaway and Youth Services
National Puerto Rican Coalition
National Women's Health Network
Rainbow Lobby
Sex Information and Education Council of the U.S.
Synagogue Council of America
UJA- Jewish Federation of New York
Union of American Hebrew Congregations

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American Association for Marriage and Family Therapy
American Association of Dental Schools
American College Health Association
American Federation Labor & Congress Industrial Organizations
American Foundation for AIDS Research
American Jewish Committee
American Nurses' Association
American Psychological Association
American Public Health Association
American Red Cross
American Social Health Association
Americans for Democratic Action
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Federation of Parents and Friends of Lesbians and Gays
Human Rights Campaign Fund
Infectious Diseases Society of America
International Association of Fire Fighters
National AIDS Network
National Assembly of State Arts Agencies
National Association for Home Care
National Association of Community Health Centers Inc.
National Association of People with AIDS
National Association of Protection and Advocacy Systems
National Association of Public Hospitals
National Association of Social Workers
National Association of State Alcohol & Drug Abuse Directors
National Coalition for the Homeless
National Council of La Raza
National Council on Alcoholism and Drug Dependence
National Federation of Societies for Clinical Social Work
National Gay and Lesbian Task Force
National Hospice Organization
National Minority AIDS Council
National Network of Runaway and Youth Services
National Women's Health Network
Rainbow Lobby
Sex Information and Education Council of the U.S.
Synagogue Council of America
United Jewish Appeal - Federation of Jewish Philanthropies of New York

NATIONAL ORGANIZATIONS RESPONDING TO AIDS

FISCAL YEAR 1991 AIDS APPROPRIATIONS REQUEST

(March 1990)

INTRODUCTION

The above signed members of the coalition National Organizations Responding to AIDS (NORA) join in urging $2,874,744,000 in spending for AIDS by the Public Health Service in fiscal year 1991. This request is about $1.2 billion above the President's request and $1.3 billion above current spending levels.

We support the largest growth in treatment and direct care programs because this has been the most neglected of the three areas of federal responsibility. As this nation faces the doubling of the AIDS caseload before the end of FY 1991, major new initiatives by the Federal government are required to provide care for those citizens and families affected by the epidemic. Assuring access to primary, acute, and long-term care services, as well as to life-prolonging drug treatments, remains the central priority in funding increases we propose in FY 1991. The major new increases proposed in this document are targeted to impact aid and early intervention initiatives necessary to provide disaster relief to the hardest hit jurisdictions and access to treatment.

The new fiscal year must also be the time when Federal programs reflect the expanded definition of AIDS prevention. Traditional education and behavior change programs must continue to grow to prevent further infection with HIV. But we must also understand that the research community has now given health care providers the tools to prevent or delay the onset of AIDS for those already infected with HIV, and Federal prevention and care programs must reflect this new reality.

The need for research does not stop with progress toward early interventions. We are far from a cure and a vaccine -- or a full understanding of HIV transmission. This work must continue and must receive increased resources. We remain convinced that AIDS research dollars should be earmarked within the NIH and ADAMHA budgets. Congress must give clear direction to the agencies regarding the priority of AIDS research. However, we remain concerned, as we have been since the beginning of the AIDS epidemic, that increases in AIDS funding not come at the expense of other important biomedical and behavioral research. We are disturbed by the inadequate levels of funding provided for non-AIDS in the FY 1991 administration request.

Not included in the PHS recommendations detailed in this document are expansions of Medicaid coverage for persons with AIDS and HIV infection. Critical to the long-term resolution of the health care access and delivery issues associated with AIDS are proposals pending before the Congress to expand Medicaid entitlements for persons with HIV infection who are not yet disabled and increased reimbursement rates for hospitals caring for persons with AIDS. Without these modifications in Medicaid, literally thousands of persons with HIV infection will face unnecessarily rapid progress to AIDS in the years ahead, and many hospitals around the country will be forced to make decisions regarding the rationing of care between indigent patients and persons with HIV disease as the AIDS burden overwhelms them.

NORA COALITION PROPOSED FUNDING LEVELS FOR AIDS IN FY 1991

PUBLIC HEALTH SERVICE
(in thousands of $)

Agency	FY1990	FY1991 (Pres.)	FY1991 (NORA)
AHCPR	8,474	10,505	10,505
ADAMHA	214,647	229,669	324,000
CDC	442,826	509,103	985,103
FDA	56,220	63,236	71,000
HRSA	112,503	72,679	524,600
NIH	743,532	800,146	950,000
OASH	7,676	8,523	8,523
IHS	------	1,013	1,013
TOTAL PHS	1,585,878	1,694,892	2,874,744

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

1991 NORA Recommendation: *$324,000,000*
1991 President's Request: *$229,669,000*
1990 Appropriation: *$214,647,000*

The Alcohol, Drug Abuse and Mental Health Administration is the federal government's lead agency in developing new ways to prevent the spread of HIV, in dealing with the drug abuse aspects of the epidemic, and in addressing the psychosocial ramifications of the disease. ADAMHA also conducts biomedical research in conjunction with NIH, particularly relating to HIV infection and the brain.

The coalition believes prevention should remain the top priority of ADAMHA, particularly given the long road ahead for development of a vaccine. We are concerned that the President's budget once again gives a disproportionate share of limited resources to neuroscience activities. The expanding demographics of HIV infection also require renewed attention to this prevention: insufficient research has been conducted regarding successful HIV prevention strategies among ethnic-minority homosexual and bisexual men, sexual partners of drug users, and adolescents -- all of whom are becoming infected at increasing rates. Priority setting in this area should be dictated by demographic incidence. We are pleased to note that ADAMHA's FY 1991 request begins to move programs in that direction.

While not part of the AIDS budget, ADAMHA's role in preventing and treating drug and substance abuse is a central part of the fight against AIDS. We continue to be

disappointed at the Administration's low level of commitment to prevention and treatment relative to the resources allocated to the war on drugs. We also believe that the ADM block grant should be administered in a manner reflecting the importance of AIDS among drug abusers.

The NORA Coalition supports the important research under way regarding neuroimmunology and psychoneuroimmunology that is not undertaken by other PHS agencies. Research into the interaction of drugs of abuse and HIV and drugs and the immune system are also important new areas directly relevant to the understanding and prevention of HIV. We believe, however, that it is important to assess what level of overlap exists between NIMH's work in this area and that of the NIH.

The NIMH's work on AIDS Dementia Complex is important. We are concerned, however, by the multiplicity of HIV-related natural history cohort studies undertaken by NIH, NIMH, and CDC. More coordination of research questions among the agencies might reduce the need for multiple cohorts, deriving valid data at a far lower cost.

Instability in funding for research and services continues to undermine the success of ADAMHA AIDS efforts. Funding fluctuations create a level of uncertainty for researchers and service providers alike, reducing potential interest competing for ADAMHA's HIV-related programs.

The NORA Coalition proposes that funds be provided beyond the President's request to support the following activities:

o $20 million beyond the President's request are needed to restore to the FY 1990 level of $33.6 million the drug abuse outreach demonstration programs. Early data from these projects suggests that it is possible to develop interventions that are highly successful in changing high-risk drug using behaviors, linking users with health care systems, and moving them off the streets and into treatment. Given that drug-related infection is the fastest growing segment of the epidemic, ADAMHA should not be phasing out these programs in FY 1991.

o $17 million should be added to maintain the number of new and competing prevention research grants at the FY 1990 level. Funding fluctuations create a chilling effect on researchers interested in studying HIV-related issues.

o $10 million are required to properly fund ADAMHA's randomized field trials of prevention interventions. ADAMHA is to be commended for initiating this long overdue program, but it can only generate the data needed if adequately funded. The $2 million in funding requested in the President's budget would not allow for creation and assessment of sound programs in multiple locations. Design of these trials should involve the CDC's prevention staff and the results of the trials should be incorporated into the CDC's prevention efforts.

o $12 million are required to fund the mental health services research demonstration program authorized by Congress in P.L. 100-607. Failure to include this in the President's request reflects ADAMHA's lack of commitment to service-based research. Mental health services are becoming an increasingly important component of HIV-related care and prevention, particularly as diagnosis is made earlier in the disease progression and there is a significantly longer life expectancy. These services also are an important component in sustaining behavior changes. Only technical assistance for this program is included in the NIMH budget, assuming that this program will be implemented elsewhere. However, the President's budget request does not fund this program elsewhere in the PHS. We believe the entire program should be part of NIMH's mission and funded at the $12 million level.

o $20 million in grants should be provided to community based prevention and service organizations focusing on drug users. Such community based efforts have been extraordinarily successful in targeting gay community prevention efforts and should be replicated for drug users.

o $10 million should be provided for outreach training and support services for substance abuse and mental health AIDS service providers to focus on outreach workers and volunteer counselors.

o $5 million is needed for research-services collaborative efforts. With an increased understanding of HIV-related behavior change in the research community, efforts must be made to bring together AIDS service providers and social scientists, including the linkage of grants issued by ADAMHA, HRSA, and the CDC in this area.

CENTERS FOR DISEASE CONTROL

1991 NORA Recommendation:	*$985,103,000*
1991 President's Request:	*$509,103,000*
1990 Appropriation:	*$442,826,000*

The Centers for Disease Control is the lead agency for HIV-related prevention activities within the Public Health Service. In that role, the NORA Coalition believes that the CDC has a responsibility to prevent primary infection with HIV, which is the object of most of its activities, and to prevent or delay, to the degree medically possible, the development of AIDS among those who already have HIV infection. It is the latter role that is the focus of our recommendation for increases in the CDC budget beyond the President's request.

The Coalition supports the increases requested in the President's budget. We especially want to highlight several of the initiatives included in the Administration request.

Increased funding for street outreach, for prevention among women and infants, and for prevention among youth are particularly important. The demographics of HIV infection point to these populations as the most vulnerable, and the least likely to have been successfully reached with the HIV prevention message. In developing these programs, we hope the CDC will be particularly mindful of the needs of gay and bisexual youth and minorities and the need to target these populations within each program.

The evaluation of alternative counseling techniques is long overdue. The prevention effort has been hampered by our failure to systematically evaluate HIV education and prevention programs. This assessment of counseling is an important first step in the right direction, and should involve the expertise of ADAMHA in this area.

The sentinel seroprevalence studies, known as the family of surveys, have provided invaluable information regarding the extent and progress of HIV infection in a number of subpopulations. The Coalition strongly supports the continuation of these studies and continues to believe these are a preferred source of information regarding prevalence of HIV infection than the proposed national seroprevalence study. While no funds are requested in the FY 91 appropriation for this very costly project, we are concerned that the CDC will attempt to redirect some of its funds to implement the household study. We believe more research is needed before moving forward with this study.

The NORA Coalition proposes an increase of $376 million, for a total of $500 million, in funds available for HIV counseling, testing, prevention education, and early intervention.

We believe such a dramatically expanded program should have two goals: (1) to counsel those at risk for HIV, whether positive or negative, regarding behavior changes that can prevent further exposure to or transmission of HIV, and (2) to provide for those already infected with HIV but not yet symptomatic the opportunity to consider treatments that have been shown to delay the onset of symptoms. We believe this fits well within the mission of the CDC since both objectives are designed to prevent the transmission or onset of disease.

The President's budget request assumes only a modest increase from $117 million to $124 million for counseling and testing services. We believe this is woefully inadequate at a time when the CDC is estimating that more than 500,000 people are in need of early intervention services. The CDC also estimates that most of these people do not know their HIV status. We believe that the CDC should be provided the funds necessary both to provide the testing and counseling opportunities and to make sure that those found positive have access to the early interventions.

We are also concerned that the increased demand for testing will further diminish the portion of counseling and testing resources devoted to counseling. It is already apparent that many counseling and testing sites devote insufficient time for effective counseling; without additional resources this could exacerbate the problem -- further weakening the value of testing.

The expanded counseling, testing and early intervention program should have four parts: (1) pre- and post-test counseling and prevention education about HIV, including a discussion of behavior changes and medical choices available for those who might test positive; (2) HIV testing services; (3) follow-up immune profiles for those who test positive to HIV to determine whether additional medical care is needed; (4) funds for early intervention drugs to be provided by either testing agencies or referral agencies for those without third party coverage. This program could in part be executed through expansion of existing arrangements with alternative HIV testing sites and the array of STD clinics, family planning clinics, TB clinics, outpatient hospital clinics, and community health centers already providing HIV-related testing, counseling and other services. We expect this program to be implemented cooperatively with HRSA.

The Coalition continues to support the CDC's funding of community based AIDS prevention and education programs among all groups associated with HIV to bring about fundamental changes in behavior and to reinforce those behavior changes that may be difficult to sustain over long periods of time. The CDC must broaden its outreach as new groups at risk are identified, without ignoring the continuing prevention needs among groups originally associated with HIV infection.

In recognition of the important basic prevention work that still needs to be implemented through the federal government's AIDS efforts, the NORA Coalition supports an additional $100 million in funding of community based prevention efforts. If these funds are channelled through the state health departments, a sound monitoring system must be established to assure that these funds actually reach community based organizations.

While we are pleased to see the evaluation component associated with counseling, we remain concerned at how little evaluation of other education and prevention programs has taken place. We are much too far along in our prevention efforts to have so little information about which approaches are successful and, therefore, ought to be replicated. To compensate for this, the Coalition proposes that Congress require a cross-program evaluation on the basis of information available from existing projects and data available from ADAMHA. Such evaluation can be one of the cornerstones of a national prevention strategy still lacking in the CDC's programming.

While not part of the AIDS budget, we support an increase to $173 million for STD prevention and control from the Administration's level funding of $81 million. The prevention and control of sexually transmitted diseases is directly related to the course of the AIDS epidemic. The behavior changes that can prevent the spread of STDs are the same that will prevention sexual transmission of HIV. This linkage is made more compelling by the role of STDs as cofactors in transmission of HIV. This substantial increase is necessary to address the alarming increase in formerly controlled STDs among heterosexuals, which could portend dramatic increases in HIV transmission as well.

HEALTH RESOURCES SERVICES ADMINISTRATION

1991 NORA Recommendation:	*$524,600,000*
1991 President's Request:	*$ 72,679,000*
1990 Appropriation:	*$112,503,000*

The Health Resources Services Administration is the lead federal agency in developing models of HIV social and health care delivery throughout the country. The Coalition is greatly disappointed that the Administration has recommended a 35 percent decrease in HRSA's funding for FY 1991. This is an unacceptable proposal for a year during which the nation's AIDS caseload is likely to double and early interventions are likely to further increase demand for care services.

The combination of programs funded by HRSA has created a necessary, although seriously underfunded, service mix to meet the growing needs for home and community based social and health care supports for people living with HIV. The mix must be sustained and expanded, especially in those jurisdictions hardest hit by the epidemic if the collapse of targeted health care delivery systems is to be avoided. The Coalition believes that more than $500 million will be needed to accommodate the considerably increased burden that will be experienced by state and local health care agencies, community based service providers, hospitals, and other primary care settings.

Over the last year, numerous sources -- ranging from academia and the press to state and local public health officials and care providers -- have described the increasingly devastating impact HIV-related care demands have had on existing systems of providing health care for the poor. Hospital gridlock and serious under-reimbursement are critical problems particularly in the highest incidence areas; community health centers and other primary care settings are overcrowded with HIV patients requiring intensive intervention; and community based organizations, which formerly kept so many individuals out of expensive hospital settings by providing critical home and community based services, are having to turn people away as their resources are stretched to the limit.

To address this crisis, the NORA Coalition calls for the immediate establishment of a $300 million impact aid program to rapidly channel necessary resources to those communities that have been most affected by HIV. Consistent with other Federal emergency programs, the resources should be targeted to local jurisdictions who will be able to allocate the funds flexibly based on priorities developed through an advisory process involving provider and consumer representatives. We expect that funds would be used to provide for the development of a range of out-of-hospital social and health care supports that would result in decreased inappropriate use of acute care settings.

The NORA Coalition also supports the expansion of the following existing HRSA programs:

o We support the doubling of funds for the adult and pediatric Health Care Demonstration programs to $68.4 million. These activities have been critical to the planning and development of consortia-based models of care that have provided a continuum of support to people with HIV disease. These consortia have emphasized more cost effective, non-hospital based care. Allocation of resources to adult and pediatric efforts should reflect incidence and demographic trends.

o The efforts of the adult and pediatric Health Care Demonstration grants are about to be supplemented by the release of new Home Health and Subacute Care grants in FY 1990. These initiatives, are an important recognition that out-of-hospital care options are a necessary component of a cost-effective continuum of care in all jurisdictions, not just those with highest incidence. The Administration has recommended defunding these programs in FY 1991. The NORA Coalition recommends funding these initiatives at $30.3 million in 1991, or $10 million above the FY 1990 level.

o During the last three years, HRSA has provided funds to states to subsidize the purchase of critical life-prolonging drugs for individuals who are otherwise uninsured or underinsured. This year, the Public Health Service announced research findings supporting expanded prophylactic use of AZT and aerosolized pentamidine. Both of these drugs have been shown to prolong life and improve an individual's health status during asymptomatic stages of the disease, often keeping patients more productive and diminishing use of acute care and other primary care services. Now is the time to expand AIDS Drug Assistance Program, not discontinue it as the President proposes. NORA therefore recommends $50 million for continuation of this program.

o Critical to the planning efforts of middle and lower incidence jurisdictions was the funding in FY 1989 of the state planning grants. The $4 million allocated that year has served to promote integrated planning efforts so that future HIV-related care needs can be anticipated before growing caseloads overwhelm primary health and social service programs. NORA recommends refunding the program in 1991 at a level of $10 million.

o As the primary care providers for many very low income individuals, the Community and Migrant Health Centers have increasingly provided services to those affected by HIV. NORA recommends expansion of the 1990 targeted funding of $10 million for the CHCs' AIDS efforts to $25 million, rather than the $13.3 million in the Administration's request. C/MHCs would also be eligible for funds under the impact aid proposal discussed above. NORA also recommends that HRSA facilitate adequate data collection efforts to assure that increasing case mixes and service needs can be adequately anticipated. NORA also urges closer collaboration between the CHCs and the NIH's clinical trials to assure better access to these trials for low-income individuals.

o A critical component of assuring the availability of subacute care settings is access to resources for facility renovations. The Administration has proposed reducing the existing AIDS Facilities Renovation grants to $4.1 million in 1991, from the current $4.2 million. NORA recommends an increase to $10 million for this program. We urge that the program permit use of these funds for residential settings for individuals with severely compromised health where health care services are provided, but not necessarily directly by the residential services operator. These funds should not be used for the renovation of inpatient hospital or skilled nursing facilities for which other capital construction or renovation dollars are available.

o NORA supports $10 million for funding of health professions faculty training, clinical skills development, and curriculum enhancement regarding AIDS, as authorized under the Health Professions Training Act under P.L. 100-607 in 1988. Current funding to implement AIDS-related curricula in health professions schools is extremely limited. Funding of this program will allow future health care providers to receive the proper

training and understanding necessary to treat AIDS patients.

o The Administration has proposed a 45 percent increase to $21 million in the resources available for the training of health care personnel at the regional AIDS Education and Training Centers. NORA proposes instead only a $2 million increase, bringing FY 1991 funding to $16.5 million. In addition, NORA strongly urges that HRSA require the linkage of the ETCs' efforts to community based AIDS primary health and social service efforts, including the HRSA Health Care Demonstration Grants program, and especially to general health providers who will increasingly be providing services to individuals with HIV. HRSA should also compile a report for Congress regarding the target service populations being served, the education models and curricula that are being developed, the potential for replicability, and the extent to which these services are being provided within community based settings.

o The NORA coalition also supports $5 million for oral health care costs, as authorized in the HOPE legislation in 1988 (P.L. 100-607). Many of the first physical manifestations of HIV infection are in the oral cavity; therefore, a dentist is often the first diagnostician to see the patient. HIV infected patients are susceptible to severe oral infections that often compromise their medical condition. A recent study concluded that oral health care is often an overlooked and unmet need of AIDS patients.

NATIONAL INSTITUTES OF HEALTH

1991 NORA Recommendation:	*$950,000,000*
1991 President's Request:	*$800,164,000*
1990 Appropriation:	*$743,532,000*

Over the last few years, there have been dramatic advances in the treatments available for persons with HIV infection and disease. These treatments are prolonging life expectancy and improving the quality of life as well. These advances have occurred as a result of a substantial investment of research dollars that must continue if more progress is to be made. While the treatments now available are important, they have not accomplished a cure or made HIV infection a chronic condition. But they do show that these are attainable goals.

Substantially more than $950 million could be spent on quality and important AIDS research. However, the Coalition is mindful of the tight fiscal constraints facing all biomedical and behavioral research. We believe that while $950 million for AIDS may be the appropriate portion of the overall NIH budget, we support substantially larger appropriations for all NIH programs, including AIDS, and are very concerned with the low growth rate for NIH generally. If the Human Genome Program, which grows by 81.4 percent or $48.5 million in FY 91, is excluded from calculations, NIH funding grows by only 4 percent, not even keeping up with inflation in the biomedical field.

The NORA Coalition is deeply concerned that the President's requested increase in funding will not permit the research community to advance the fight against AIDS sufficiently in fiscal year 1991. Many of the NIH programs are funded through multi-year contracts and grants whose negotiation has assumed substantial growth in the out years. All the institutes have had to "downward negotiate" both competing and non-competing grants in FY 1990. NIAID, for example, has reduced AIDS and non-AIDS grants by 14 percent in FY 1990, with the exception of the AIDS Clinical Trial Groups, which are being cut by six percent. With even smaller growth in the President's budget in 1991, we fear more severe cuts will be required -- or no new initiatives will be fundable, even if new avenues of research open up.

In this context, we believe the $150 million recommendation above the President's request will still require some very difficult decision making regarding priorities in the NIH AIDS research program. We urge that highest priority be given to treatments, particularly the much neglected research into opportunistic infections that actually cause illness and death among persons with HIV infection. These have been given very belated attention, and we urge that they be given the highest priority in fiscal year 1991 allocations.

We support a substantial increase in funding for the NIAID's Community Program in Clinical Research on AIDS (CPCRA). Drugs to treat OIs have not received as much interest from the pharmaceutical industry and the academic scientific community as anti-retroviral treatments. For example, the AIDS Clinical Trial Groups, the centerpiece of the NIH's clinical research on AIDS, have been reluctant to take on research into opportunistic infections. On the other hand, much of the dramatic progress that has occurred around OIs has taken place through community based research. Since progress in this area will result in the quickest short-term gains for persons with AIDS, and the per-patient cost of community research is lower than in the current ACTG structure, expansion of CPCRA is a wise investment. CPCRA was unable to fund many highly rated proposals in its initial round of awards and we support the NIAID's plans to increase the number of awards in fiscal year 1991. The President's budget does not permit the level of expansion deemed necessary by the agency, and we support an additional $13 million for this program.

Given the late start that NIH efforts on opportunistic infections have received, we are particularly hopeful that there will be substantial expansion of the National Cooperative Drug Discovery Group Program for the Treatment of Opportunistic Infections. We are concerned that the President's request does not provide sufficient resources for the NCDDG-OI to assure that this program move as rapidly as possible in gaining the capacity already in place for anti-retroviral drug development, nor does it provide adequate related programming in toxicology support, chemical and pharmaceutical support, and development of animal models. We support the additional $10 million deemed necessary in the professional judgment of the agency.

Development of treatments for HIV itself must also continue. We are concerned that one of the most promising programs, NCI's preclinical drug screening project, is funded at such a low level that it only has the capacity to develop three or four compounds a year. If more are discovered, the NCI budget justifications warn that licensing arrangements will have to be made with the private sector to continue research and development. We believe that sufficient flexibility should be given the NIH budget to permit NCI and NIAID to move forward without having to be totally dependent on private sector interest or initiative.

Continued growth in government funded clinical trials is necessary to support study of both the expanded number of possible therapies and the combination therapies that are being developed. Indeed, comparison and combination trials of drugs produced by different manufacturers may only be possible under government auspices. This requires adequate support for both the ACTG and CPCRA systems. We support an additional $9 million for the ACTG program, as deemed necessary in the professional judgment of the agency.

The continued growth in pediatric and adolescent AIDS cases and the special research questions associated with treating pediatric AIDS and conducting trials with pregnant women demand greater attention from the three NIH institutes working on pediatric AIDS: NCI, NICHD, and NIAID. The delays in assessing the value of AZT for children, for example, point to both management and fiscal deficiencies in the pediatric AIDS research program. We support an additional $23.3 million for pediatric trials at the NIH.

The Coalition supports greater coordination of comparable AIDS research efforts. For example, the integration of the pediatric clinical trials conducted by NICHD and NIAID are important to assure coordination of research and to be more cost effective. We hope that similar demands will be made on the AIDS Clinical Trial Groups, which represents the overwhelming portion of clinical research funding by the NIH. Several studies and hearings have shown tremendous discrepancies in productivity among the sites funded. Many of the ACTGs are up for recompetition in fiscal year 1991, and we see this as a potential source of tighter fiscal control.

While we acknowledge the NIH for its efforts to be more inclusive of all populations affected by HIV in its clinical trials, we continue to be concerned that women, minorities, and substance abusers remain under-represented. The CPCRA has been particularly successful in this regard and we urge that in reviewing the ACTGs for renewal that they be held to a similar standard. Trials of pregnant women and active drug users, for example, while rejected in the past must be part of the study of HIV if effective treatments and cures are to be found for all affected by AIDS. In addition, NIH should be urged to collaborate with HRSA-funded AIDS service grants and community health centers to improve access to clinical trials by underserved populations.

We believe that the NIH has seriously neglected its responsibility to understand all aspects of the AIDS medical crisis by providing only marginal resources for behavioral research efforts. These should be substantially increased and more advantage should be taken of integrating behavioral research with the biomedical research already under way (such as incorporating behavioral research issues with populations already included in clinical trials of drugs).

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

1991 NORA Recommendation:	*$10,505,000*
1991 President's Request:	*$10,505,000*
1990 Appropriation:	*$ 8,474,000*

While a relatively small portion of the PHS's AIDS budget, the health care research conducted by this agency is critical to planning and understanding of the scope of the HIV epidemic. The NORA Coalition is very supportive of all efforts to define the costs associated with HIV-related care and the impact of various medical and care-related advances. We hope the results of this research will be given greater attention by the political decision makers within the Administration, who have often ignored the economic impact studies of HIV on our nation's health care system.

OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH

1991 NORA Recommendation:	*$8,523,000*
1991 President's Request:	*$8,523,000*
1990 Appropriation:	*$6,439,000*

The funds appropriated to the OASH are to support the work of the National AIDS Program Office ($3.9 million) and the HIV-related work of the Office of Minority Health ($4.6 million).

The coordination and leadership roles of NAPO are important for an integrated and non-duplicative national AIDS program. We hope that as NAPO becomes a more established arm of the AIDS effort that it will have the capacity and authority to develop a true

national AIDS agenda and that it will not become enmeshed in bureaucratic details of individual agencies.

The work of the Office of Minority Health brings an important perspective to AIDS prevention efforts as they affect minority communities. Given that the bulk of minority education efforts are funded through the Centers for Disease Control, close coordination and care that duplication is avoided are necessary.

FOOD AND DRUG ADMINISTRATION

1991 NORA Recommendation:	*$71,000,000*
1991 President's Request:	*$63,236,000*
1990 Appropriation:	*$56,220,000*

While not part of the Labor-HHS appropriations bill, the work of the FDA, as part of the Public Health Service, is obviously a critical component of the fight against AIDS. FDA, perhaps more than any other agency involved with AIDS, has been crippled by space and staffing shortages that have seriously delayed the review of promising AIDS therapies. Dramatic progress has been made in this regard for AIDS drugs, but similar movement has not been as apparent for other diseases.

The NORA Coalition endorses the overall FDA recommendations of the FDA Council. Included in those recommendations are additional funding for the AIDS research building on the NIH campus and training of AIDS researchers. We are especially supportive of the expanded computerization of the drug approval process. We also support $10 million for expansion of the discretionary grant program under the Orphan Drug Act.

We join the FDA Council in urging that the FDA's activities be funded out of general revenues, and that growth in FDA staff and programs not be dependent on the implementation of user fees, as is suggested in the President's budget. If the need for these expanded services is there, and we believe it is, they should be implemented and not side-tracked by the debate over user fees.

OTHER HHS PROGRAMS

National Commission on AIDS

We endorse the President's request of $3 million for funding of the National Commission on AIDS. The Commission has begun a vital assessment of the nation's AIDS response and will, in its second year, offer major recommendations for implementing a comprehensive response to this health crisis.

Office of Human Development Services (OHDS)

Within the Administration for Children, Youth, and Families, we support additional funding for three programs that target youth at risk to HIV infection. We support $35 million in funding for the Runaway and Homeless Youth program, as compared to the President's request for level funding at $28.8 million. This program funds nearly 350 community-based centers that provide short-term shelter and other crisis intervention services to help reunite youth with their families. It also supports regional coordination of services, national hotlines, and discretionary grants. Reportedly, at least 3,000 young people are turned away from these shelters each year because there are not enough beds.

Life on the streets increases the chances for HIV infection as teens, lacking skills, education, and experience, often practice "survival sex" to meet basic needs of food and shelter, and use drugs to escape the harsh reality of street life. While these funds are not directly used for AIDS, they address the underlying causes of risky behavior among disenfranchised adolescents. These shelters are often the only organizations in their cities and communities that are currently housing minors who are HIV-infected; in addition, many are instituting HIV-prevention programs.

We also support $15 million for the Transitional Living Grant Program for Homeless Youth, as opposed to the President's request for level funding at $9.867 million. This program is designed to provide residential and other services to homeless youth "to promote a transition to self-sufficient living and to prevent long-term dependency on social services." This program also attempts to keep young people off the streets, thus ameliorating many of the conditions that contribute to HIV transmission.

We urge $20 million for the Drug Abuse Prevention Program for Runaway and Homeless Youth, as compared to the President's request for level funding at $14.8 million. This program supports community efforts to prevent drug use and to provide early intervention services to high-risk youth. Again, the emphasis is on deterring young people from practices that can have devastating health consequences, including the transmission of HIV.

AIDS Action Council
AIDS National Interfaith Network
American Academy of Pediatrics
American Anthropological Association's Task Force on AIDS
American Association for Counseling and Development
American Association for Marriage and Family Therapy
American Association of Dental Schools
American College Health Association
American Federation Labor & Congress Industrial Organizations
American Foundation for AIDS Research
American Jewish Committee
American Nurses' Association
American Psychological Association
American Public Health Association
American Red Cross
American Social Health Association
Americans for Democratic Action
Center for Women Policy Studies
Chronic Fatigue Syndrome Information Institute Inc.
Citizens Commission on AIDS
City of New York
Committee for Children
Consortium of Social-Science Associations
Federation of Parents and Friends of Lesbians and Gays
Human Rights Campaign Fund
Infectious Diseases Society of America
International Association of Fire Fighters
National AIDS Network
National Assembly of State Arts Agencies
National Association for Home Care
National Association of Community Health Centers Inc.
National Association of People with AIDS
National Association of Protection and Advocacy Systems
National Association of Public Hospitals
National Association of Social Workers
National Association of State Alcohol & Drug Abuse Directors
National Coalition for the Homeless
National Council of La Raza
National Council on Alcoholism and Drug Dependence
National Federation of Societies for Clinical Social Work
National Gay and Lesbian Task Force
National Hospice Organization
National Minority AIDS Council
National Network of Runaway and Youth Services
National Women's Health Network
Rainbow Lobby
Sex Information and Education Council of the U.S.
Synagogue Council of America
United Jewish Appeal - Federation of Jewish Philanthropies of New York

PREPARED STATEMENT OF DEBRA FRASER-HOWZE

GOOD AFTERNOON LADIES AND GENTLEMEN OF CONGRESS, I AM GRATEFUL FOR YOUR INVITATION TO GIVE TESTIMONY. I AM HERE TODAY TO SPEAK FOR THE PEOPLE WHO HAVE NOT HAD A STRONG VOICE IN THIS EPIDEMIC, A PEOPLE WHO WERE BEING DEVASTATED BY EXCESSIVE DEATH RATES LONG BEFORE AIDS. A PEOPLE WHO NOW MAKE UP 61% OF THIS DISEASE IN NEW YORK CITY, THE BLACK AND HISPANIC NEW YORKER. AFRICAN AMERICAN AND LATINO CHILDREN MAKE UP 90% OF ALL INFECTED CHILDREN WITH AIDS IN NEW YORK, THIS IS A VERY DIFFERENT DISEASE IN COMMUNITIES OF COLOR, IT IS A DISEASE THAT IS KILLING OUR CHILDREN.

MY NAME IS DEBRA FRASER HOWZE AND I AM THE EXECUTIVE DIRECTOR AND CHIEF EXECUTIVE OFFICER OF THE BLACK LEADERSHIP COMMISSION ON AIDS. THE COMMISSION WAS FORMED IN 1987 WITH 69 MEMBERS OF THE CITY'S BLACK LEADERSHIP, CONSISTING OF A CROSS SECTION OF CLERGY, POLITICIANS, SOCIAL POLICY EXPERTS, BUSINESS AND MEDICAL PROFESSIONALS. THE COMMISSIONS GOAL IS TO IMPROVE THE HEALTH CARE AND SERVICES TO AFRICAN AMERICANS INFECTED WITH AIDS AND THEIR FAMILIES, THROUGH PROVIDING TECHNICAL ASSISTANCE IN MANAGEMENT AND FUNDING TO COMMUNITY BASED ORGANIZATIONS,POLICY FORMATION, ADVOCACY,AND PROGRAMS THAT ADDRESS MASS EDUCATION AND COMMUNITY DEVELOPMENT,AND A VERY SPECIAL DEVELOPMENT PROGRAM FOCUSING ON PRODUCING ADDITIONAL SERVICES THROUGH THE AFRICAN AMERICAN CHURCH.

61% OF PEOPLE WITH AIDS IN NEW YORK CITY ARE NOW BLACK AND HISPANIC, NEW YORK HAS THE LARGEST AIDS CASE LOAD OF OVER 24,000 IN THE UNITED STATES. 84% OF THE WOMAN IN NEW YORK WITH THIS DISEASE ARE WOMAN OF COLOR. RESEARCHERS HAVE ESTIMATED THAT THERE WILL BE 50-73,000 CHILDREN ORPHANED BY AIDS IN THE NEXT FEW YEARS AS A RESULT OF THIS. I STAND WITH THE PEOPLE WHO HAVE CHOSEN TO TRY AND MAKE A DIFFERENCE IN THIS EPIDEMIC IN COMMUNITIES OF COLOR AND I CAME HERE TODAY TO TELL YOU THAT THE WAR IS ABOUT TO BE LOST.

A RECENT ARTICLE IN A PRESTIGIOUS MEDICAL JOURNAL EXAMINING EXCESSIVE DEATHS IN COMMUNITIES OF COLOR STATED THAT A BLACK MAN IN HARLEM HAS LESS OF A CHANCE OF LIVING TO THE AGE OF 65 THAN A MAN IN BANGLADESH. THIS STUDY WAS BASED ON 10 YEAR OLD DATA THAT PROCEEDED THE RAVISHES OF CRACK AND AIDS, WHICH CAN EASILY BRING THAT LIFE EXPECTANCY FIGURE TO 40 OR LESS. WHY SHOULD A BLACK MAN IN A CITY IN AMERICA HAVE TO DIE EARLIER THAT A MAN IN BANGLADESH? THE INFANT MORTALITY RATE IN OUR COMMUNITIES RESEMBLED THOSE IN UNDEVELOPED NATIONS... BEFORE AIDS. ABOUT ONE IN EVERY 60 BABIES BORN IN MANHATTAN IN 1988 WERE HIV POSITIVE AND THE PICTURE GETS WORSE AS WE GET TO SOME AREAS OF THE BRONX WITH FIGURES OF ONE IN EVERY 44.

THERE ARE WAITING LISTS FOR ADMISSION IN OUR HOSPITALS SO TERRIBLE THAT IT CAUSED THE EMERGENCY ROOM DOCTORS AT A HOSPITAL IN BROOKLYN TO WALK OUT IN PROTEST WITH OVER 38 PEOPLE WAITING IN THE HALLWAYS OF THEIR EMERGENCY ROOM FOR A BED WITH CRITICAL

ILLNESSES,FOR OVER THREE DAYS. THE HETEROSEXUAL EPIDEMIC HAS HAPPENED IN NEW YORK CITY, WHERE WOMAN OF COLOR WHO ARE PRODUCTIVE AND VIABLE MEMBERS OF THE SOCIETY ARE DISCOVERING THEIR INFECTION FOR THE FIRST TIME BECAUSE THEIR CHILDREN HAVE BECOME SICK AND ARE DYING.

OUR COMMUNITY IS UNDER SIEGE... THE CRACK HOUSES ARE FLOWING WITH ADOLESCENTS WHO ARE PART OF THE" HEAD BANKS". THEY REFER TO THE BEAUTIFUL YOUNG GIRLS WHO DEPOSIT THEIR BODIES IN THE HANDS OF THE CHIEFTAINS OF THE CRACK HOUSE, WHO MAKE THEM PERFORM ORAL AND VAGINAL SEX WITH HIS CLIENTS AS PAYMENT FOR CRACK AT TWO DOLLARS AN ACT ON THE AVERAGE OF 12-14 HOURS A DAY. AS A RESULT, GONORRHEA OF THE THROAT IS NOW INDICATED AS A GROWING PHENOMENA FOR THESE YOUNG WOMAN, ALONG WITH OTHER SEXUALLY TRANSMITTED DISEASES. WE KNOW FOR A FACT THAT THEIR IS A CONNECTION BETWEEN CRACK AND AIDS. I SUBMIT TO YOU, WE ARE LOOSING THE WAR AGAINST AIDS AND DRUGS IN COMMUNITIES OF COLOR IN NEW YORK.

WHEN THIS DISEASE FIRST PRESENTED ITSELF IN NEW YORK IT APPEARED IN A SMALL ARTICLE ON THE BACK PAGES OF THE NEW YORK TIMES AND IT WAS CALLED GRID, FOR GAY RELATED IMMUNE DEFICIENCY DISEASE. COMMUNITIES OF COLOR HAVE BEEN CRITICIZED FOR NOT COMING FORWARD IN THIS EPIDEMIC YET WE DID NOT HAVE THE SUFFICIENT INFORMATION, NOR THE RESOURCES. NOW THAT WE HAVE THE INFORMATION, AS WE WATCH DEATH RATES IN OUR COMMUNITIES RISE TO UNPRECEDENTED LEVELS WE STILL DO NOT HAVE THE RESOURCES. WE ARE USING WHATEVER WE CAN TO ADDRESS THIS ISSUE, WE'VE BEEN AT THE TABLE NIGHT AND DAY SINCE 1987, WORKING TO SAVE THE LIVES OF OUR PEOPLE. WE ARE STRAINING THE LIMITED RESOURCES OF COMMUNITY BASED ORGANIZATIONS AND HAVE

ENLISTED THE HELP OF THE BLACK CHURCH TO INITIATE SERVICES AND EDUCATION AND PREVENTION PROJECTS BUT THEY ARE ALREADY OVERLOADED SIMPLY BURYING THE DEAD. BUT IT IS NOT ENOUGH, THE DISEASE IS WINNING, AND WE KNOW IT BECAUSE 90% OF THE CHILDREN INFECTED IN NEW YORK ARE BLACK AND HISPANIC, AND WHEN WE LOSE OUR CHILDREN WE HAVE LOST IT ALL.

WE CAN NOT DO IT ALONE, WE MUST HOLD EVERYONE RESPONSIBLE FOR WHAT IS ABOUT TO HAPPEN, IF WE DO NOT GET MORE RESOURCES TO COMMUNITIES OF COLOR FOR BOTH PREVENTION AND TREATMENT. OUR COMMUNITY NEEDS MORE EDUCATION ON THIS DISEASE, BLACK WOMAN IN NEW YORK BELIEVE THAT YOU HAVE TO BE SLEEPING WITH AN INTRAVENOUS DRUG USER WHO IS NODDING ON A CORNER, TO BE AT RISK OF INFECTION. THEY HAVE NOT BELIEVED THAT THEY CAN GET THIS DISEASE AS A RESULT OF ONE UNPROTECTED SEXUAL ENCOUNTER WITH ANYONE WHO IS A CARRIER.

IF YOU CAN FIND IT NECESSARY IN YOUR HEARTS TO APPROPRIATE EMERGENCY FUNDS FOR PEOPLE WHO HAVE LOST THEIR HOMES AND/OR PROPERTY AS A RESULT OF NATURAL DISASTERS, THEN SURELY YOU MUST FIND IT IN YOUR HEARTS TO APPROPRIATE EMERGENCY FUNDS FOR A CITY AND ITS COMMUNITIES WHO ARE LOSING THEIR CHILDREN.

WE ARE LOSING THE WAR ON AIDS,IN COMMUNITIES OF COLOR IN NEW YORK CITY. WE THE PEOPLE ON THE FRONT LINES CAN NO LONGER CONTAIN THIS DEVASTATION ON OUR COMMUNITY. WE ARE WEAK, WE ARE TIRED AND WE ARE CRYING OUT FOR YOU TO HELP US AT LEAST CATCH UP WITH THIS DISEASE, BY HELPING US TO EDUCATE,TREAT AND PREVENT.

AIDS IS A HETEROSEXUAL DISASTER EVERYWHERE YOU GO IN THESE COMMUNITIES. WE NEED SOME NEW AMMUNITION IN THE WAR ON AIDS AND DRUG ABUSE. YOU HAVE GOT TO SEND A MESSAGE TO OUR CHILDREN AND OUR

PEOPLE TO COME IN OFF THE EDGE. THE PRESIDENTS BUDGET DOES NOT REFLECT THAT SAME NEED.

I AM HERE TODAY REPRESENTING AN ORGANIZATION THAT REFLECTS THE DIVERSITY OF THE INFECTED AFRICAN AMERICAN COMMUNITY. WE NEED PROGRAMS TO MEET THE NEEDS OF THE PEOPLE WE REPRESENT, WE NEED ALLOCATIONS THAT GET TARGETED APPROPRIATELY. WE NEED TO BE INCLUDED IN SOME OF THE DECISIONS THAT ARE MADE AND WE NEED TO BE ABLE TO USE RESOURCES TO EDUCATE OUR COMMUNITY THE WAY WE KNOW THEY NEED TO BE EDUCATED, AND WE NEED YOUR HELP TO DO IT..... WE IMPLORE YOU TO ASSIST US IN THIS CRISIS OR THE WAR WILL BE WON , NOT BY THE INFECTED COMMUNITY BUT BY THE DISEASE.

PREPARED STATEMENT OF MARIE ST. CYR-DELPE

Congresswoman Boxer, Task Force Members. I am Marie St. Cyr-Delpe. On behalf of the Women and AIDS Resource Network (WARN) in Brooklyn, New York, I am pleased to present my views on the needs for AIDS education, prevention, research and treatment to the Task Force on Human Resources. While I serve as Executive Director at WARN, I also sit as a board member of the National AIDS Network and know that WARN's story is repeated in many places throughout the country.

WARN was created in 1986 to respond to the unmet need of women as it relates to HIV and AIDS. Since that time we have witnessed alarmingly increasing numbers of women who are getting diagnosed as well as those who are seeking information to assess their individual risk and the implications for their families. In 1987 WARN registered 27 women in its caseload. In 1988, with 89 women we almost tripled our caseload, and in 1989 we served over 112 women and their families. These women have an average of 2.7 children - over 300 youngsters involved, a large number of whom are already orphaned as a result of AIDS.

Lately our concerns are intensified as we encounter multiple diagnoses among siblings. In one particular family, a 61 year old mother faced HIV positivity of 3 children in a four month time period. For the 26 year old daughter, the first diagnosed, early intervention, clinical trials, or alternate trials were not available until after her first bout with pneumocystis carinii

pneumonia. With our intense education intervention in the family, the other two siblings will have a chance at a better health outcome with earlier interventions through medical therapies and psychosocial support.

I share this case to pave the way to the following proposals. Early intervention has been defined today to mean drugs like AZT, Pentamidine and Bactrim, monitoring, and some primary care. Important as these things are, early intervention must be redefined to encompass efforts undertaken before the individual becomes infected. Meaningful behavior intervention and prevention activities must become the starting point of early intervention.

In the history of the HIV epidemic, we, as a nation, have reacted to each group shown in the surveillance data diagnosed with AIDS (gay white men, intravenous drug users , babies and women). We maintain a crisis-oriented approach along with the traditional curative approach to health care. The incubation period of the HIV virus renders obsolete and dangerous our methodology.

Without a cure or a vaccine, prevention efforts must be aggressive and targeted, and the commitment to them must be national, if not global, in scope.

The client population whose needs WARN addresses are often the last to receive services - that is, access to information, options to participate in clinical trials, and therapies.

Who are these women? Who are these families? Over 75% black and Latino women, who live for the most part in Brooklyn and Manhattan, in poor disenfranchised communities with the least resources to sustain the burden of HIV and AIDS.

Our communities are in need of localized prevention outreach which encompasses and takes into consideration traditional modalities and institutions effective and credible among the population: Church and church programs, schools, grass root community groups, the neighborhood, the local leadership.

My concern is that in embracing early medical intervention, we give up or reduce to minimal our prevention efforts and the allocation of resources for the continuum of psychosocial support needs of those tested and still asymptomatic and, more particularly, those not yet infected.

In the neighborhood where I am working, I am appalled, and you may be frightened, at the youth scene. Babies are having babies - you see nothing that makes their lives significant - their schools are inadequate, their family life fragmented, their sidewalks are permanently leased to drug dealers, in their schoolyards crack and ice are the offered as recreational stimulants. They are losing siblings and parents to violence, to many other diseases and now to AIDS. What was a desperate situation has been made so much worse. In Harlem, for instance, a recent study released shows that

black men's life expectancy was comparable to that of men in Bangladesh (65 years old), before AIDS.

Ladies and gentlemen, we only have to look at the increasing rate of sexually transmitted diseases, the rate of teen pregnancies, the unwanted pregnancies, teenage runaway and associated sexual activities, increases in crack use in spite of the war on drugs, lack of drug treatment slots, the absence of drug treatment for mothers with their children, the sexual activities associated with drugs, to realize that we are at the very beginning in terms of meaningful HIV prevention efforts. Each of these other societal ills functions as a very powerful cofactor in the transmission of this new disease.

In our clearinghouse of information, the age of concerned callers ranges from 13 to 68 years old. Increasingly, those who seek information are less and less the stereotype we have assumed for those women at high risk of HIV infection. They remind me of the large number of women and men in recovery; they remind me of the sexual adventurers of the 70s; and of the perception in the early 80s that women were beyond the grasp of HIV. They remind me that in education/prevention, the very false underlying assumption was that people will make logical deductions and act accordingly to prevent infection and transmission of HIV.

We face today, a sense of complacency and disregard to HIV and AIDS, particularly among those who feel they do not fall under a

risk category or those who may have experiences which increase their risk, yet are so overwhelmed with trying to survive that AIDS is the last issue on their list. I am referring to those who amy be homeless, who may be sick with addiction and others who are living on the borderline.

There is a great urgency I feel around establishing a comprehensive prevention and treatment agenda. But to be successful, the approach must englobe other human needs before and beyond HIV. If not, then we make a conscious, or, at best unacknowledged, decision to lose these lives. A collaborative effort and partnership between the local service providers and consumer groups, local and state governments, and decision makers like yourself is essential to making a true difference in our communities.

Essential in maximizing utilization of therapies is that we integrate a continuum of services in our delivery. The notion of treatment of HIV includes an array of medical approaches which compels us to add clinical trials, unconventional therapies to the treatment options. The reality is that treatment options are not available unilaterally - minority populations, women have had minimal access and in some neighborhoods, no access.

Underfunded community based programs, privately supported CBOs like WARN continue to appeal to city/state/federal <u>funders</u> to develop appropriately modeled services, specific to local neighborhoods which impart a sense of proprietorship and responsibility to make

and support changes in their own milieu.

Ten years of prevention efforts, however underfunded, have forced us to discard the assumption that fear of death will compel behavior changes. A fragmented prevention strategy which has sought to minimally educate targeted population groups among which an escalation of AIDS diagnosis continues can hardly be said to have been effective. This is not an indictment of the methodologies. They have simply been too underfunded and too fragmented. They have also not allowed for the type of ongoing support sustained behavior changes require.

Why? because there has been no national commitment to prevention. What we really need is to urge you to embrace a prevention agenda so that we won't have to face the lives shattered and lost, and the cost to this country, and my neighborhood.

A national prevention strategy is in order. If it is good and effective, it will also be costly... but not as costly as it will be if such an agenda is not embraced. Your input is needed to formulate such strategy and allocate resources to make it a reality. If you are thinking "not the whole nation" needs to deal with HIV prevention, think again. Failure to educate and promote real behavior change through targeted education will threaten the future of all of us, not just those of us who happen to live in Brooklyn or Harlem. This is my appeal. I hope you can respond.

PREPARED STATEMENT OF KATHLEEN SHERIDAN

Good afternoon and thank you for this opportunity to present testimony on the issue of AIDS prevention funding. My name is Kathleen Sheridan, I am here today on behalf of the American Psychological Association (APA) and the National Organizations Responding to AIDS (NORA). I am an Associate Professor in the Department of Psychiatry and Behavioral Sciences and am Deputy Director of the Comprehensive AIDS Center at Northwestern University. I am also involved with NIH-funded Multicenter AIDS Cohort Study (MACS) and am a member of the American Psychological Association's Task Force on AIDS and the Chicago Department of Health's AIDS Advisory Council.

Since 1983, APA has worked actively to develop an appropriate national response to the AIDS epidemic. Many of the most critical issues facing us are behavioral: in the face of a disease that clearly can be prevented, and in the absence of a vaccine or cure, how can we prevent transmission of the virus that causes disease? This issue falls squarely within the province of psychology, a field which has developed a very strong research literature on the correlates and modification of human behavior. It is natural then that APA should co-chair the Prevention Task Force of the National Organizations Responding to AIDS (NORA), a 150 member coalition of organizations whose members are dedicated to addressing the AIDS epidemic. Along with our co-chair, the American Public Health Association, we work to ensure that principles of behavioral intervention are considered as we try to prevent further viral spread.

While I represent national associations today, I also come as a voice from the midwest...where the picture of AIDS is very different than that found on either coast. It is a picture of lower numbers of diagnosed cases of AIDS. But it is not therefore a place where the rates of new infections should be assumed to be low. The scientific literature and prior testimony to Congress have documented the very rapid spread of the virus once it is introduced into communities. And recent data which I will present later indicate that despite the relatively fewer numbers of diagnosed AIDS cases, the midwest is currently experiencing extremely high rates of new infections with the virus that causes AIDS.

These figures have ominous implications for the future disease burden and sustained sexual and perinatal transmission into the next century. If there is one message that is uniform through the country, it is that we don't need ounces of prevention. We need a few pounds. And if there is one message which the coastal experiences have taught us already, it is that these few pounds of prevention, even if marginally effective, will prevent the expenditure of billions of dollars in cure later.

The federal government has a grave responsibility to insure that prevention efforts are continued and expanded commensurate with the potential for an exponential growth in new cases of HIV infection. I intend to make the case for this need using the Illinois example as an indicator for the rest of the nation.

There are several key points I would like to emphasize at the outset.

- The epidemic is not over and the numbers of new infections will continue to increase.

- Despite the advent of some promising interventions to forestall ultimate development of frank AIDS among the HIV infected population, prevention of the spread of HIV infection must still be one of our chief priorities.

- We are far from winning our prevention war--though some populations at high risk for infection have altered their behavior there are many individuals who have not heard the prevention message, who don't believe the message applies to them, or who have changed their behavior but are slipping back to higher risk activities.

- Any tension that may appear to exist between prevention and treatment dollars is misguided: These programs clearly serve different populations in an effort to reduce the incidence of disease.

- In order to improve our ability to prevent the spread of the virus we must know more about which prevention efforts work and which don't work in specific populations. This means we need a strong commitment to on-going research activities.

CASE STUDY: Chicago and Illinois

The epidemic of AIDS is discussed as an East Coast-West Coast phenomena. Indeed much of the public perception drawn from media reports has focused on the special circumstances of cities like New York, San Francisco and Los Angeles. Certainly these communities have borne the brunt of the epidemic throughout the early 1980s and have been leaders in the development of a response to the human tragedy of the disease. But there is another aspect of this epidemic that I would like to present to you today, one that suggests the more dispersed nature of this crisis, and the continuing great need for prevention resources.

The case study is that of Illinois and its largest urban center, the city of Chicago. While Chicago ranks among the ten cities in the United States with the highest number of AIDS cases, the downstate portion of Illinois is representative of the rapid dissemination of the virus into rural and semi-urban America.

Illinois, with 3,225 cumulative cases of reported AIDS and 2,307 cases of HIV infection reported to the state health department, has an urgent health care crisis of enormous proportions. Yet this is the mere tip of the iceberg. The reported numbers of HIV infections are believed to be an underestimate of the extent of HIV infection in the state. With hundreds of thousands of additional at-risk individuals among drug users, gay and bisexual men, women, adolescents, ethnic-minorities and others, the need for continued and expanded prevention efforts is somewhat daunting.

Of the 102 counties in the state, 78 are now reporting cases of AIDS to the state health department. Since 15% of these counties in Illinois do not

have local health departments many of our rural communities are without the administrative mechanism to deliver AIDS prevention efforts. In 1989, the state received $1 million in federal AIDS education/ risk reduction funding and supplemented this with $877,000 in Illinois state funds. These figures do not include dollars for counseling and testing programs or federal dollars channelled through direct grants from federal agencies or through the U.S. Conference of Mayors. Nevertheless, for a state with a population of 11.5 million this averages less than 16 cents per individual for targeted AIDS prevention efforts.

We are making good use of the dollars provided us; I will demonstrate that through six vignettes of the AIDS prevention scene in Illinois. We are using or creating effective models for AIDS prevention activities. We currently do outreach in a few communities in Chicago alone, while dozens of other in the city and throughout the state require immediate prevention services. The programs I will cite together present a small proportion of the education/prevention efforts we are undertaking but they show what kinds of programs can work. Through this snapshot of AIDS prevention, I will show how increased resources are needed to really address the future waves of this epidemic.

In presenting this picture of prevention, I will draw upon the work done for The AIDS Strategic Plan for the City of Chicago which was submitted to Mayor Daley on October 25, 1989. This document, which was prepared by the Chicago AIDS Advisory Council on which I serve, contains an excellent section on AIDS prevention and education activities that could be used as an example of national prevention funding needs at the local level. I would like to submit this section for the record. Of the programs I am going to describe, which represent only a handful of the prevention efforts in our state to date, the first is conducted under the auspices of a grant from the National Institute on Drug Abuse (NIDA), while the other four are coordinated by the Comprehensive AIDS Prevention and Education Program (CAPEP) which is funded by the Centers for Disease Control (CDC). Many of these efforts are of necessity labor intensive given the complexity of

changing the intimate and self-reinforcing behaviors that contribute to the spread of the virus.

I am not going to address the programs of counseling and testing on which Illinois spends $3.4 million, with 62 percent coming from the federal government. These programs are useful in assisting individuals in changing their high-risk behaviors, largely through the counseling component which is an essential part of the education/risk reduction effort. These are not the programs, however, that teach individuals the necessary skills to change risk behavior. Moreover, the public and political focus on HIV testing has provided these initiatives with a political imperative that does not exist for the risk reduction/behavior change efforts.

DRUG ABUSE

Left unchecked, the second wave of HIV infection fueled mainly by drug use and spread through sexual and perinatal transmission, will create a pool for sustained transmission well into the 21st Century. I cite as an example the borough of the Bronx, New York, where HIV transmission was left largely unchecked in the early years of the epidemic. Let us be clear: As a result, the levels of infection among young adults in the Bronx approach those reported in the young adult population in Central Africa.

The National Institutes on Drug Abuse (NIDA) is now funding relatively small university-based intervention projects in 63 major cities across the country. These are the only federally-funded efforts which directly target the user on the street to prevent the further spread of the AIDS virus. These are outstanding programs but they do not event begin to address the thousands of other industrial towns and cities where IV drug users are known to share contaminated equipment.

Chicago is fortunate to have one of the NIDA funded outreach prevention projects designed to reach IV drug users before the epidemic is out of control. But even as one of those cities where a start has been made immediate increases in effort are required. Nevertheless for many it will

be too late: The Chicago AIDS Strategic Plan has estimated that approximately 14,00 to 20,000 Chicago IV drug users have already been infected with HIV. An additional 56,000 to 70,000 regular users of intravenous drug remain at risk for infection. If Chicago follows the pattern of HIV spread among intravenous drug users (IVDU's) in other cities there could be and additional 5,000-7,000 infections among Chicago IVDU's in the next 12 months. At least 90% of these IVDU's are not in drug treatment.

Allow me to put this in perspective for you, with regard to the coastal experience. Just a few months ago, Dr. Wayne Wiebel of the University of Illinois documented that about 10% of infected IV users are currently becoming infected in Chicago each year. These are as high as the highest rates of infection published to date for any community in the United States.

Treatment is a viable intervention to stem the spread of AIDS but, as in the rest of the country, there are far too few drug treatment slots existing in Chicago to meet the growing demand. In 1988 there were 2,045 admissions to IV drug use treatment slots in Chicago, providing coverage for only 3% to 4% of the estimated 70,000 IVDUs in the city. Despite increases in treatment slots through the various federal wars on drugs in recent years, the numbers of IVDUs not in treatment will continue to exceed the capacity. Thus the dominant method for reaching the IVDUs with AIDS prevention is through street outreach programs.

In the absence of increased treatment capacity what does the outreach picture look like? At the Chicago AIDS Outreach Intervention Project funded by NIDA, persons skilled in working with the homeless and substance abusers oversee "street workers." The latter, typically former drug abusers, circulate in neighborhoods, establishing personal contact with drug users providing information and education about risk reduction. These outreach workers teach the drug users the means to protect themselves and others from HIV infection, primarily by demonstrating methods to clean needles and syringes, distributing bleach and also by encouraging the use of condoms.

The Chicago effort has had some notable successes. Recent data suggest that out of 561 clients in one such outreach project, 25% entered treatment and 14% stopped injecting. Other data from around the country suggest that these programs promote significant increased bleach use. In San Francisco, the NIDA program reports that the proportion of IVDUs cleaning their drug paraphernalia increased from 6 percent in 1985 to over 70 percent in 1988. These reports have also suggested that these programs are an ideal method for getting the street IVDU in contact with the public health system, educating them about safer sex practices and actually moving them and into drug treatment programs.

Initial data have also suggested that these prevention programs are extremely cost-effective. A study published in the Journal of the American Medical Association (JAMA) suggests that with each street outreach worker (at an annual salary of $30,000 a year) seeing 600 IVDUs on a regular basis within a given year, the cost per accessed IVDU is $50. If the street outreach worker is only 25-50% effective in eliminating HIV infection among those contacted, the cost of successful interventions is $100-$200 per year per IV drug user. While outreach is no substitute for moving an IV drug user into treatment/rehabilitation, this intervention can be viewed as a cost-effective method of preventing HIV transmission until there are additional resources for treatment.

Using information about the activities of nine outreach workers from the Chicago NIDA project during two sample weeks from the summer and winter of 1989, the average weekly number of contacts for 1989 was 1,974. Of these, there was an average of 439 new contacts each week, and 1034 were repeat contacts. According to the Chicago AIDS Strategic Plan, three different programs are providing AIDS education and prevention services to the Chicago IVDU population. The NIDA program has worked with over 40% of the estimated 30,000 IVDUs contacted. This leaves over 55,000 IVDUs who have not been contacted through AIDS prevention efforts. Using a figure of $150 as the average cost of a successful IVDU contact (one that eliminates HIV risk) as suggested by the JAMA article, the cost of reaching 40% of the remaining IVDU population through the NIDA project would be $3.5 million.

WOMEN AND AIDS: A LOOK AT SERVICES TO ONE SUBPOPULATION--FEMALE PROSTITUTES

Nationally, women account for almost 10 percent of the total number of cases of AIDS in the adult population with Black and Hispanic women constituting almost three-quarters of this group. To date women have primarily been viewed as vectors or transmittors of infection rather than as a discrete entity requiring specialized approaches and knowledge in and of themselves. As a result we know precious little about the most effective ways to provide AIDS education and prevention services to women, particularly the cultural pressures that may impact uniquely on populations of ethnic-minorty women at risk.

While prevention efforts directed towards women have tended to be broad-based and general, there are groups of women, which often overlap, whom may be at increased risk of infection and consequently in need of more specific approaches. IV drug use is the primary source of HIV infection among women in Chicago accounting for nearly 45% of the city's female AIDS cases and placing 10,500 to 22,500 women at risk of infection. Many women in Chicago who do not inject drugs are placed at increased risk by the drug using behaviors of their sexual partners. The Chicago plan projected this population at somewhere between 27,650 and 37,500 women. In addition because of the relationship between women and pediatric AIDS cases, there is no way to prevent this disease in babies other than by keeping women uninfected.

In our case study we look at one of the three programs in our city which include prostitutes in their target populations. The AIDS intervention program of Genesis House, which is the only one designed specifically to address and meet the needs of prostitutes, conducts street outreach in 6 different high-crime areas of Chicago, as well as 2 courtrooms in the Cook County courts. The program targets the large number of street prostitutes who exchange sexual favors for money or for drugs. The outreach workers (most of whom are former prostitutes) make daily visits to assigned areas during "businesshours" (late afternoon, evening and nighttime). These

outreach contacts occur on street corners, in bars and restaurants, and in any other areas requested by female prostitutes.

On average, a two-person outreach team makes 1,620 outreach contacts during the course of a year. Between 50% and 65% of these contacts are repeat interventions. Over a period of time, outreach helps to increase each woman's level of AIDS awareness, helps her to assess her personal risk level, provides her with techniques for reducing her risk, and reinforces her risk reduction practices. The intervention program provides its client population with the means of empowerment by distributing free condoms and AIDS-prevention literature, sponsoring formal educational sessions and support groups. Preliminary information indicates that prostitutes who have frequent contact with Genesis House outreach workers are more likely to: 1) use condoms with customers and other sexual partners; 2) attempt to find out if their sexual partners are active IV drug users; and 3) attempt to leave prostitution or reduce their number of sexual partners.

The Genesis House AIDS prevention program provided street-based outreach and formal AIDS education services to 4,299 female prostitutes at a per capita coast of $32.30. Based on their extensive experience, Genesis House staff estimate there are at least 25,000 female prostitutes in Chicago proper. If correct, these figures suggest there are 20,000 female prostitutes remaining to be served. A city-wide intervention program based on Genesis House's per capita expenditures and employing its intervention model (that is, street-based outreach to minority group female prostitutes) would require additional funding of $650,000 a year.

THE CASE OF YOUTH: RUNAWAY, HOMELESS, AND GAY ADOLESCENTS

Over 5,500 cases of AIDS in adolescents and young adults under the age of 25 were reported to the CDC as of December 1989. Although this accounts for less than 5% of the overall total of cases of AIDS nationwide, this statistic hardly accounts for the number of adolescents who were infected as youths or young adults, given the incubation period of 10 years or more from infection to frank AIDS. Many authorities believe that adolescents present

the next major vector for spread of the virus largely because of their feelings of invulnerability, their high rates of sexual activity and their experimentation with various high risk behaviors.

Out-of-school youth are those who have been ejected from or have voluntarily dropped out of the traditional school setting. Several subgroups exist within the population of out-of school youth including the homeless, runaway and "throwaway" youth, those incarcerated and gay or bisexual street youth. As with other groups there may be overlap between these somewhat arbitrary categories. Not only will these youth miss the risk reduction efforts provided through formal school-based programs but by virtue of their out-of-school status they may be more likely to lead lifestyles in which sexual relationships and drugs are seen as solutions to problems rather than problems themselves. While young males experimenting with same sex sexual activity may or may not be in school, uncertainty about their own sexual identity, potential lack of contact with the gay community and social inhibitions which force them to remain in the closet present a considerable challenge for prevention efforts. Our next two vignettes address these groups.

Neon Street Center for Youth provides AIDS prevention education to runaway and "throwaway" youth, many of whom live on the streets and have engaged in prostitution to support themselves. Ninety-five percent of Neon Street's client population are from Illinois. Seventy-five to eighty percent of the clients are male, and 55% are Black. Their ages range from 13 to 20. Almost all of its male and female youth report having had sex in the past six months often in conjunction with alcohol or drug use and only 36% reported always using condoms.

The program conducts a drop-in center for runaway youth, a temporary housing program for up to 45 homeless youth and employs two outreach workers to provide street-based AIDS interventions to runaway male youth prostitutes. Formal AIDS prevention programming at the Neon St. Center includes individual counseling and risk assesment, informal spontaneous gatherings revolving around salient current issues, and weekly seminars on a

full range of AIDS-related educational topics. Preliminary information on program effectiveness indicates that both male and female participants engage in prostitution less often than before, have reduced their number of sexual partners, are more selective of their sex partners and use condoms on a more frequent basis.

Neon Street's drop-in program serves approximately 400 youths per year. Its outreach program to male hustlers reaches another 60-70 youths on a regular basis. In 1989, these combined programs provided regular AIDS-prevention education to approximately 450 high risk runaway teenagers at a per capita cost of $150.00. Current estimates of the numbers of runaway-throwaway teenagers in Chicago range from 2,500 to 12,000; the most frequently mentioned figure is 10,000. Based on these figures, a city-wide program incorporating Neon Street's AIDS intervention model could require additional expenditures ranging from $307,500 to $1.8 million. These costs do not include the antecedent costs of providing food, shelter, clothing or medical care to this large population.

Horizons Community Services Youth Program provides AIDS-prevention education to self-identified gay youth. Approximately 65% of Horizons clientele are male, 45% are Black and 25% are Hispanic. Ninety-two percent of the male population had sex in the past year; these same 92% also stated they had recently had sex while under the influence of drugs or alcohol. Twenty-three percent said they never used a condom.

Horizons goals of promoting and reinforcing safer sex group norms are accomplished through an informal drop-in policy, an open house and more structured AIDS prevention programs. This process personalizes the issues for youth program members and fosters both formal and peer socialization for newcomers. As a result the "veteran" participants are able to act as role models for the younger participants and encourage behavioral change through a group normative process.

In 1989, the Horizons Youth Program served approximately 4,000 participants, mostly from minority backgrounds. The per capita cost was

$146. Although a precise count of gay and lesbian youths in Chicago remaining to be served by AIDS prevention programs is not possible, Horizons' administrators estimate the probable number range from 35,00 to 40,000. An expanded program designed to reach an additional 1,000 gay and lesbian minority youths would cost at least $146,000 while a program for 40,000 more participants would cost $5.8 million.

JAIL INMATES

Cermak Health Service provides medical treatment and psycho-social counseling to the inmates of Cook County Jail. Although 99% of the 419 males interviewed reported having sex in past 5 years, only 8% always used condoms during that period while 41% never used condoms. Fifty-six percent of the male respondents said they had more than one sexual partner in the 90 days prior to their incarceration. Moreover, 23% reported sexual relations with at least one male partner, and 9% admitted having sex with other men during their current period of incarceration. Finally, 43% of the male respondents said they had injected drugs at least once during their lifetime.

The Cermak AIDS Education Program provides intensive formal AIDS education in small group settings. In the men's division, a male Health Educator convenes groups of 8 to 10 inmates to participate in two educational sessions three days apart. The initial session employs a variety of means (lectures, audiotapes, videotapes, books, and pamphlets) to convey basic information on AIDS, HIV transmission and AIDS prevention. The second session generally provides more detailed information on specific questions generated by the initial meeting.

Cermak staff report significant improvement in knowledge about AIDS prevention and intend to cease high risk behaviors. In 1989, a total of 445 inmates successfully completed the Cermak AIDS Education Program at a per capita cost of $145. At present, approximately 6,550 inmates remain to be served. Extrapolating costs of the current program, a jail-wide intervention program could be offered to the entire population of 7,000

inmates for an annual cost of $947,000 or an increase of $882,650 over current expenditure levels.

AREAS OUTSIDE CHICAGO

In the downstate region of Illinois, that area outside of the Chicago metropolitan region, there have been 392 cases of diagnosed AIDS and 416 cases of HIV infection reported to the state health department. A recent press release from the Illinois Department of Public Health indicates that the number of downstate cases increased by 92 percent between 1988 and 1989 and that the doubling rate for AIDS is now similar to that of Chicago three or four years ago.

There remains a great deal of denial that this disease is anything other than a big city phenomenon. With this denial, and with very limited funds, it is unlikely that adequate prevention and education activities are occurring. But the problem is real: Although national attention to the problem of urban AIDS is focused most heavily on Chicago, the communities in and around Peoria, Decatur, Springfield, Rockford, Champaign, and East St. Louis are all experiencing significant case loads.

In these communities the cost of denial maybe a major factor hampering prevention efforts. One research project from the downstate area reports great resistance among parents to AIDS-related education programming in the schools around East St. Louis. We are also hearing from researchers in these communities what we have heard on the coasts: AIDS education does not equate to behavior change. Increasingly, Americans even in semi-rural parts of the country know what AIDS is and how it is transmitted but they don't necessarily have the skills or commitment to change behavior suggesting the massive need for experientially-based AIDS prevention programs. Another East St. Louis project working with the clients of a sexually transmitted disease clinic reports on the value of prevention efforts there: a thorough-going AIDS prevention effort can increase the condom use of this high risk population. But in possibly the most alarming data from this region of the

state, over time college students have as great a risk for HIV infection as the clients of a nearby STD clinic.

Moreover, there is a potential hidden epidemic in even the most rural of areas. Last summer, national attention was focused on the small town of Mt. Carmel, Ill. when the CDC reported on an outbreak of non-A/non-B hepatitis. This community, with a population of less than 5,000, had no reason to believe that there was a significant IV drug using problem, yet this form of hepatitis is closely linked with IV drug use. And upon investigation by local, state and public health authorities, it appeared that drug use was indeed associated with this outbreak. Although the illegal drugs injected by users in rural America are not necessarily the same kinds of substances used in our big cities--meth amphetamine, "crystal" and "crack" appear to be more of a problem in these areas--the routes of adminstration provide a fertile opportunity for the spread of HIV to spread in non-urban America.

OTHER PREVENTION ISSUES

There are numerous other issues of prevention in Illinois; we have touched only the surface of the problem. One example is with gay and bisexual men who nationwide continue to account for the largest share of the AIDS cases. It has been clear from around the nation, that a major change in behavior of historic proportions occurred among gay and bisexual men during the 1980s. Data from the Chicago's Howard Brown Memorial Clinic, a community-based agency targeting AIDS health services to gay and bisexual men, indicates that over time the number of new HIV infections has dropped to extraordinarily low levels mirroring the dramatic change in the sexual behavior of gay men across the country. It is the community-based agencies like Howard Brown that have provided much of the education and prevention efforts in the gay community to date. Their efforts must not be forgotten and their programs must continue to receive ongoing support.

There are, however, prevention concerns in Illinois that reflect the concerns nationwide: discrete groups of men who have not been able to reduce

their high risk of behaviors. Moreover, indications from the first wave cities of the epidemic suggest that problems with maintaining behavior change over time may develop among pockets of individuals in all populations unless programs to reinforce behavior change are set into place.

In dealing with other populations at risk, special concern must be taken in the design of prevention programs to insure that they truly reach the targeted audience. The methods and materials developed for the gay and bisexual community to insure behavior change, will not translate into programs that adequately address women, ethnic minorities and adolescents. The unique cultural and social characteristics of the discrete population sub-groups must be fully considered in developing appropriate and useful materials. Research on behavior change have taught us that empowering communities to develop their own health interventions is really the most effective method for insuring their adoption.

This broad overview of prevention activities and concerns within the state is only a modest indicator of the extent of programs now underway and more importantly the expanding need for interventions and resources. While the populations and the nature of the infections differ from state to state throughout the heartland of this country, the massive need for continued and expanded programs is consistent. The lessons of the Illinois example also show us that the initial funding of prevention efforts begun in the 1980s have provided us with model programs that can be adopted in other localities.

It is only with increased support from the federal government, however, that this process of identifying successful models of prevention interventions and replicating them in other communities can occur. To do so requires a major commitment: For example to expand the five programs I have described to reach the populations at-risk in Chicago alone would require an investment of over $15 million. Even if a federal-state matching program were fiscally feasible for our state, this would require increasing the federal commitment by seven fold. And across the country, hundreds of communties require similar infusions of resources in order to reach the

populations most at risk for AIDS. The massive scope of the crisis at hand requires this kind of large scale investment of the federal government to insure the continued health of Americans not now infected with the virus.

THE NORA BUDGET REQUEST FOR PREVENTION

By comparison with the scope of the need, the AIDS prevention budget request prepared by the National Organizations Responding to AIDS (NORA) is modest. We seek to fund the prevention programs supported by the Public Health Service (PHS) at the level requested by the agencies administering these programs. The Centers for Disease Control (CDC), which has the primary responsibility for AIDS-related health promotion and disease prevention, and the Alcohol and Drug Abuse and Mental Health Administration (ADAMHA) which develops and models prevention activities, are the lead PHS agencies in this regard. Aside from the $500 million for the NORA early intervention prevention program as discussed by earlier witnesses to expand counseling and testing programs throughout the United States, we ask for $789 million, or $319 million over the FY 1990 level of expenditure. This sum is $342 million over the President's FY 1991 budget request for non-counseling/testing prevention activities.

In addition to the initiatives proposed by the President, some of the additional activities funded by this increase would include:

o $20 million to restore the funding cut of $20 million in the NIDA drug abuse outreach demonstration programs as contained in the President's FY 1991 budget proposal. These programs, like the project in Chicago are highly successful in changing high-risk drug using behaviors, linking users with health care systems, and moving them off the streets and into treatment. Given that drug-related infection is the fastest growing segment of the epidemic, ADAMHA should not be phasing out these programs in FY 1991.

o $17 million to maintain the number of ADAMHA new and competing prevention research grants at the FY 1990 level. ADAMHA will not be able to continue the work it has undertaken unless stable levels of funding are maintained. Funding fluctuations create a chilling effect on researchers interested in studying HIV-related issues.

o $10 million to properly fund ADAMHA's randomized field trials of prevention interventions. ADAMHA is to be commended for initiating this long overdue program, which has been recommended by the National Academy of

Sciences and is designed to determine the most effective community-wide approaches to prevention interventions comparing several communities against each other. But such a program can only generate the data needed if adequately funded. The $2 million in funding requested in the President's budget would not allow for creation and assessment of sound programs in multiple locations. Design of these trials should involve the CDC's prevention staff and the results of the trials should be incorporated into the CDC's prevention efforts.

o $12 million to fund the mental health services research demonstration program authorized by Congress in P.L. 99-601. Failure to include this in the President's request reflects ADAMHA's lack of commitment to service-based research. Mental health services are becoming an increasingly important component of HIV-related care and prevention, particularly as diagnosis is made earlier in the disease progression and there is a significantly longer life expectancy. These services also are an important component in sustaining behavior changes. Only technical assistance for this program is included in the NIMH budget, assuming that this program will be implemented elsewhere. However, the President's budget request does not fund this program elsewhere in the PHS. We believe the entire program should be part of the NIMH's mission and funded at the $12 million level.

o $20 million in grants to be provided to community based prevention and service organizations focusing on drug users. Such community based efforts have been extraordinarily successful in targeting gay community prevention efforts and should be replicated for drug users. This request also allows for expanded funding to these gay-community organizations, with a continued special focus on ethnic minority concerns.

o $10 million for outreach training and support services for substance abuse and mental health AIDS service providers to focus on outreach workers and volunteer counselors.

o $5 million for research-services collaborative efforts. With an increased understanding of HIV-related behavior change in the research community, efforts must made to bring together AIDS service providers and social scientists, including the linkage of grants issued by ADAMHA and CDC in this area.

o This budget will allow continued expansion of the sentinel seroprevalence studies, known as the family of surveys, conducted by the CDC which have provided invaluable information regarding the extent and progress of HIV infection in a number of subpopulations.

o These funds will permit the evaluation of alternative counseling techniques designed to produce behavior change in the context of HIV testing a long overdue addition to the prevention effort.

Thank you for the opportunity to testify. I am happy to answer any questions.

AIDS
Action
Council

FOR IMMEDIATE RELEASE
March 6, 1990

FOR MORE INFORMATION: Contact Tom Sheridan,
AIDS Action, (202) 293-2886

AIDS Service Providers Support Kennedy CARE Bill

Endorsing Senator Kennedy's AIDS care bill in Washington this morning, Jean McGuire, Executive Director of the AIDS Action Council called the measure "the relief for community based organization that will mean the difference between survival and bankruptcy". The "Comprehensive AIDS Resources Emergency Act" (CARE) of 1990 provides for $500 million in federal assistance to states and localities to provide for urgently needed health care and social services.

"This bill is the product of crisis, compassion and competence" said Tim Sweeny, Chair of the AIDS Action Council's Public Policy Committee. "Crisis-- because our systems are collapsing as the epidemic continues to double each year. Compassion--because despite the rhetoric of many, all Americans can agree that care for those who are ill is necessary and important. Competence--because this bill builds upon and supports existing structures of services and seeks to intervene in the earliest and most cost effective manner".

Praising the bi-partisan support this bill has received to date, Pat Christen, Executive Director of the San Francisco AIDS Foundation said "With the support and leadership of Senators Kennedy, Hatch, Cranston and Wilson I am hopeful that this emergency measure will be passed in time to save the crumbling service system in San Francisco and throughout the country".

Currently AIDS service organizations throughout the United States have provided the backbone of AIDS related prevention, education and care. "Until today the US Congress has not been an equal partner in finding solutions to the unmet care needs of people with AIDS and HIV infection" said McGuire. "The unprecedented voluntary contributions of many Americans has given us a nine year grace period but sadly the epidemic grows worse and the private resources cannot keep pace. Only federal action of this type can ensure that existing systems of community-base care, particularly for the poor, do not collapse under the weight of the epidemic".

The measure as proposed by Senators Kennedy and Hatch provides a total of $500 million for both state assistance and planning as well as immediate funds to the thirteen cities that have the largest number of AIDS patients to date. The combination of emergency assistance and state planning funds is intended to act as both a short term solution and a long term plan for what is expected to be the most difficult of the AIDS related policy challenges.

Jean McGuire joined Elizabeth Taylor, Mayor David Dinkins, Dr. June Osborn, Senator Kennedy, Senator Hatch and a host of other AIDS leaders for a Capitol Hill ceremony this morning as the bill was introduced to the Senate.

The AIDS Action Council was formed in 1983 by community based service providers seeking a federal response to the AIDS epidemic. It is now the only AIDS specific lobby in Washington and represents over 500 non-profit community based service providers throughout the United States.

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[Whereupon at 5:02 p.m., the Task Force was adjourned.]